

Research report

Developing a clearer understanding of the Carer's Allowance claimant group

Gary Fry, Benedict Singleton, Sue Yeandle and
Lisa Buckner

Department for Work and Pensions

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A report of research carried out by the Centre for International Research on Care, Labour and Equalities, School of Sociology and Social Policy, University of Leeds on behalf of the Department for Work and Pensions

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Abbreviations

| | |
|---------|---|
| AA | Attendance Allowance |
| ADASS | Association of Directors of Adult Social Services |
| BAME | Black and Minority Ethnic |
| CA | Carer's Allowance |
| CAU | Carer's Allowance Unit |
| CES | Carers, Employment and Services study (University of Leeds, 2007) |
| DCS | Disability and Carers Service |
| DLA | Disability Living Allowance |
| DOH | Department of Health |
| DWP | Department for Work and Pensions |
| HoC WPC | House of Commons Work and Pensions Committee |
| HoC PAC | House of Commons Public Accounts Committee |
| ICA | Invalid Care Allowance |
| IS | Income Support |
| JSA | Jobseeker's Allowance |
| LGA | Local Government Association |
| NAO | National Audit Office |
| NCS | National Carers Strategy |
| NMW | National Minimum Wage |
| SP | State Pension |

Summary

In the past few years there has been considerable attention to the situation of carers, including new national policies intended to address many of the problems which arise in the provision of care. Taken together, official, grey and academic literature provide an increasingly detailed picture of the circumstances, perceptions, views and behaviour of carers as a group; and partly as a result of this strong body of evidence carers are now recognised as a heterogeneous, dynamic and important group, comprising a large number of people in many different situations.

The evidence base on those carers who regularly provide substantial care and who are also eligible to claim Carer's Allowance (CA) is, perhaps surprisingly, less detailed. Few studies have been carried out with large numbers of CA customers, and relatively little is known about this group of carers, their caring roles, and how they manage to negotiate their caring roles while receiving CA. This study was commissioned by the DWP to address these issues and to find out more about the CA customer group.

In 2009 there were 526,620 carers claiming CA (DWP figures¹). Approximately 20 per cent of CA claimants in payment were aged 18-34 years, with a further 70 per cent aged 35-59. Women outnumbered men in all age bands except age 60-64. Those who receive CA are, by definition, carers with particularly demanding caring roles, providing 35 or more hours of care per week to people with severe disabilities.

This study aimed to increase understanding of carers in receipt of CA. It investigated how carers come to claim CA, carers' situation in relation to other state benefits, and their experiences in accessing CA. It focused particularly on the caring roles of CA customers, on how they cope with their daily caring responsibilities, and on how CA fits in with these roles, examining their experiences of paid employment, decisions concerning employment and/or education, and the role CA plays in these decisions.

Research data for the study was collected using a mixed methods approach. These included:

- interviews with carer advisors specialising in CA claimants;
- a postal survey of CA claimants (just over 500 completed questionnaires);
- eight group discussions with CA claimants in four localities in the UK;
- individual interviews with a sub-sample of CA claimants drawn from the survey respondents (Chapter 3).

CA claimants who took part in this study had characteristics very similar to those of carers in the official CA data at a national level. This suggests the CA survey respondents were reasonably representative of CA claimants more generally. Respondents in the study were predominantly female and of different ages (as are all CA customers); most were working age white British carers. Half the carers in the sample had no formal qualifications (Section 4.1).

Most relied on some assistance from support services (often having struggled to access them) and on informal help from friends and family. Most found the services they had managed to access inadequate, and above all desired more opportunities to take a break from caring (Section 4.2). Most had accessed CA because their caring responsibilities had grown onerous, limiting their access to

¹ Data acquired from the latest DWP statistics at the time of writing.
<http://research.dwp.gov.uk/asd/>

paid employment (Section 4.3). Many were also claiming other benefits, though some felt that there was a stigma attached to seeking such support. Others had experienced difficulties in accessing CA (and other benefits and services), including struggling to find relevant information about what was available, difficulties in understanding how different benefits interacted, and confusion over the rules which applied to each (Section 4.4).

Most of the respondents in this study had been caring for a considerable time, very intensively, and in difficult financial circumstances. The onset of care had involved a period of adjustment which had affected carers' domestic situations and employment opportunities, often resulting in feelings of low esteem and poor health. Carers were providing many different types of care, ranging from personal care to practical assistance (e.g. helping out with paperwork). Most CA claimants in the study were caring for a child, a parent or a spouse/partner, and there were some significant differences between these groups (Section 5.1).

The overwhelming majority of carers found that their CA payment had to be used as part of their household income which covered everyday costs (e.g. paying utility bills), though some wished they could spend it on themselves (Section 5.2). Many carers felt that the care they provided was an important contribution to society and said that a lack of acknowledgement of this role made them feel unappreciated. Most carers felt that claiming CA affected their lives in many ways, including limiting employment/study opportunities, adding confusion to their caring roles, and having a lack of money (Section 5.3).

Most CA claimants in this study were caring for someone full-time, and only a very small number were in paid employment. Compared with carers at the national level (Census 2001 data), these carers were far less likely to be in paid work. Many had been forced to give up work soon after the onset of care, usually because they had needed more time to care or had been unable to negotiate suitable working hours with their employer (Section 6.1).

Others had taken a part-time job because they wished to remain in employment; this, it was felt, offered them many psycho-social benefits (e.g. better health and friendship) as well as keeping them in touch with the job market, with a view to returning to full-time paid employment when their caring role ended or changed. A large majority of carers said they would prefer to have a paid job when their caring role ended, though many had found it difficult to work while caring and receiving CA (Section 6.2). The eligibility rules for CA (principally the weekly earnings limit) were regarded as overly restrictive, and suitable jobs which accommodated their often highly complex caring situations were regarded as few and far between (Section 6.3). A minority of carers did not wish to be in paid employment because they felt that working would compromise their caring role, which they were unwilling to allow to happen (Section 6.4).

The key findings of the study (Sections 7.1-7.3) are as follows:

CA customers' access to benefits and services

CA plays an important role in many carers' lives and is a crucial source of income for some carers, although some carers in the study had tried to survive financially for long periods without applying for it, anticipating difficulties and frustrations in doing so. For many in the study CA was just one part of a complex package of support, drawn from a variety of sources which enabled them to fulfil their caring role and responsibilities.

Many carers in the study were angry about how difficult it had been to access what few formal services they had managed to get in place. For most, accessing CA had involved challenges and many said obtaining information and advice on CA had not been easy. Most carers were using CA as part of their everyday household budgeting, or for specific care needs; it was very rare for CA to be used for anything other than daily necessities.

CA customers' experiences of caring

Carers of older people were less likely than other carers to live in the same household as the person they cared for, and were the least likely of all in the study to be claiming three or more state benefits. Many reported financial difficulties and said they would prefer to be in paid work. Long-term care had had a particular impact on the financial welfare of this group.

Carers of a child were the most likely to be in paid employment; most of these carers were women who were working part-time. This group was the most likely to have a higher level of qualification, but included many who said they were experiencing financial difficulties and who were claiming two or more state benefits.

Long-term carers were more likely than other carers to be in poor health; many in this group provided very high weekly hours of care (100+ hours per week). Long-term carers were also the most likely to have abandoned once-held aspirations, including hopes for their career. Many worried about their lack of pension contributions and feared for their own welfare in old age.

Nearly half the sample had no qualifications and these carers (and those with only lower level qualifications) were more likely than those better qualified to be caring full-time and to be receiving two or more state benefits. Those carers with a higher level of qualification were more likely to be a student, to be retired, and to be caring for a child, and were more likely to say that they had found it difficult to find a job which put their qualifications to use.

CA customers' decisions about paid employment

Most in the study thought jobs with a fixed number of hours and flexible enough to accommodate carers' complex caring responsibilities were very difficult to come by. Carers who wished to return to education and/or develop new skills which would later give them an advantage in the job market reported that the 21 hours rule for studying while claiming CA made it difficult to access courses.

Half the respondents in the survey had given up work at the onset of their caring role. Difficulties in adjusting existing employment to accommodate care had often occurred despite employers being sympathetic to carers' responsibilities. Some CA claimants had managed to alter their working hours, usually to enable them to remain within the eligibility criteria for CA, and part-time work was valued as it enabled them to retain or develop work skills and keep in touch with the job market.

Although most expressed a desire to work once their caring role had ended, and nearly a third would have preferred to be in paid employment at the time of the study, only four per cent were actively looking for a job. Carers suggested that this was because the eligibility rules for CA were very restrictive, making finding suitable work extremely difficult. Those few carers in the study who were in paid work highlighted the advantages they felt were involved in having a job, including benefits for their health, self-esteem and confidence.

Not all carers in this study wanted to work; some regarded the care they provided as a 'full-time job' and emphasised that carers are not 'unemployed'.

The key recommendations of the study (Section 7.4) are as follows:

Key aims for the carers in the study were to feel better supported in their caring role, to have a 'life of their own', and to secure paid employment, aspirations consistent with the 'vision' set out in the National Carers Strategy (NCS) 2008 and reiterated in the Next Steps Carers Strategy (HMG 2010). Different parts of the system of support and services for carers should, therefore, be 'joined up' in practices and design, especially in the context of growing 'personalisation' in the social care system. Co-ordinated, holistic help is needed.

Additionally, a more ‘human’ approach, and a sounder appreciation of many carers’ very demanding caring roles, is needed to deliver re-designed support appropriately. To be effective, Carers Direct should be promoted widely and tasked with delivering a high quality, up-to-date service. There should be clear information about the support available to carers, with clarity about CA a part of this, in line with obligations under the Carers (Equal Opportunities) Act 2004. In addition, information about CA should be available to carers from the first moment they access support or services.

Preventative action in the system of care and support is greatly needed. Many carers feel they get no help, or do not seek access to formal support, until they encounter a ‘crisis’ and say this has a negative impact on their health. More investment in preventative approaches is recommended, to avoid unnecessary damage to carers’ health and help them hold on to paid employment if they wish.

The eligibility rules for CA are problematic for carers seeking paid employment or training. They limit them to low paid unskilled work, and a narrow range of courses; these rules should be reviewed. Carers also experienced some difficulties and confusion in the way CA interacted with other benefits. This should be addressed, especially in relation to how CA relates to Income Support (IS), but also to respond to carers’ view that CA is ‘taken away’ when they reach retirement age. In making any changes to CA, it is recommended that its importance as an acknowledgement of caring roles be retained: this may involve separating different elements of the financial support carers can claim.

CA customers are more likely than other carers to be in poor health. Carers in this study who reported that their health was ‘not good’ (132) represented 26 per cent of respondents. This is very much higher than the figure seen in the general population (2001 Census) among people of working age who have no care responsibilities (eight per cent), and it is also considerably higher than the figure (derived from the 2001 Census) for all carers who provide 50+ hours of care per week and whose health was ‘not good’ (17 per cent) (Buckner and Yeandle, 2005). It is recommended they be targeted in future efforts to promote carer health and wellbeing. Poor carer health leads to additional costs in the health and social care system, and concerted efforts are needed to address these.

Most carers in the study had given up paid work to care, despite their belief that combining work and care is important for carer wellbeing. It is recommended further effort be put into providing a wider range of support services for working carers and raising employers’ awareness of the role they can play. To be effective, this needs to happen alongside adjusting the earnings limit rules for CA.

1 Introduction

1.1 The context for the study

In the past few years there has been considerable attention to the situation of carers, including new national policies intended to address many of the problems which arise in the provision of care. Many voluntary organisations have responded to these developments by collecting evidence about carers' situations, and the academic and official evidence base on the lives and circumstances of carers has now been building for over 20 years. Taken together, the official, grey and academic literature provides an increasingly detailed picture of the circumstances, perceptions, views and behaviour of carers as a group; and partly as a result of this strong body of evidence carers are now recognised as a heterogeneous, dynamic and important group, comprising a large number of people in many different situations.

The evidence base on those carers who regularly provide substantial care and who are also eligible to claim Carer's Allowance (CA) is, perhaps surprisingly, less detailed. It is widely acknowledged that many carers face great difficulties, often experiencing negative impacts on their financial situation and their health, and feeling socially excluded. Those who receive CA are, by definition, carers with particularly demanding caring roles, providing 35 or more hours of care per week to people with severe disabilities. In 2009 there were 526,620 carers claiming CA (Department for Work and Pensions (DWP) figures). Approximately 20 per cent of CA claimants in payment were aged 18-34 years, with a further 70 per cent aged 35-59. Women outnumbered men in all age bands except age 60-64. A fuller understanding of the CA customer group is particularly important given continuing debate about how best to meet their needs for financial support.

1.2 Study aims

In seeking to gain a clearer understanding of the CA customer group, this study adopted a mixed-methods approach, combining a literature review, analysis of published statistics on CA customers, secondary analysis of an existing data set which included interviews with carers receiving CA and new empirical research, using a variety of approaches, conducted specifically for this study. The methods used in collecting new data are outlined in Chapter 3 and detailed in the report appendices. The study research questions fell into three categories, relating to:

- **CA customers' benefits history** – what are their experiences of state benefits and how does this relate to CA?
- **CA customers' experiences of caring** – what is the nature of their caring circumstances and how do they manage to negotiate them?
- **CA customers' decisions about paid employment** – how and why have they taken decisions to give up paid work, to reduce their working hours or to change their job or seek more flexible employment? Where applicable, how and why have they decided to return to employment?

1.3 Structure of the report

The report is structured as follows. After introducing the study and its approach in Chapter 1, Chapter 2 provides a review of previous literature relating to carers and CA (drawing on material produced over the past five years). Chapter 2 thus provides a background and context for the study;

the evidence presented in it informed the design of the research. The chapter also includes a brief summary of evidence from a large study of carers, the Carers, Employment and Services (CES) study, reported in 2007, which was selectively re-analysed to highlight the responses of those participants who had experience of claiming or receiving CA (Yeandle *et al.*, 2007a-c). Chapter 3 describes the research methods used in collecting data for the new study commissioned by DWP in autumn 2009.

Chapters 4, 5 and 6 explore the new data collected and present the main study findings. Chapter 4 describes the sample of respondents and explores their benefits profile. Chapter 5 considers the caring situations of the CA customers included in the study and presents their views on these in the context of their status as recipients of CA. Chapter 6 considers how CA impacts on carers' paid employment decisions, the importance of paid work for carers, and if, how, and to what extent they manage to remain in paid work while receiving CA. The final chapter (Chapter 7) summarises the key findings of the study and makes recommendations intended to contribute to debates on future policy on carers and CA.

2 Background

This chapter briefly summarises previous research on carers and Carer's Allowance (CA). It opens by discussing the policy context, considering key issues in how CA functions as a benefit, and then discusses evidence from earlier studies about how carers' decisions and behaviour in the labour market are affected by CA.

2.1 Introduction

There is now wide consensus in the available literature that demographic and social change and developments in healthcare continue to increase the need for care, a need which in the UK is often supported by paid care workers and professional services, but relies heavily on a large number of unpaid carers, mostly people caring for family members (CSCI 2009; Yeandle and Buckner, 2007; Yeandle, 2009).

In April 2001 approximately 10 per cent of the UK population were regularly looking after a relative, friend or neighbour on an unpaid basis (Census 2001); this amounted to around six million people, of whom three-quarters were people of working age (Buckner and Yeandle, 2006). A range of studies have shown that carers pay a triple penalty, with their health, finances and social inclusion all negatively affected, especially when care is long term and intensive (Willmott, 1986; Phillips *et al.*, 2002; Arksey *et al.*, 2005; Yeandle and Buckner, 2007). Those who provide the most unpaid care are the most likely also to be permanently sick and disabled themselves, and are the least likely to be in paid employment (Singleton *et al.*, 2002; Buckner and Yeandle, 2005; Dahlberg *et al.*, 2007).

Studies have also repeatedly indicated that carers often need financial support in their everyday caring roles and have difficulties in combining caring with employment, many having to give up paid work to care (Bytheway and Johnson, 1998; Stiell *et al.*, 2006; Yeandle *et al.*, 2006). A growing body of literature has also acknowledged the diversity of carers' circumstances and characteristics, and many commentators have noted the need to adapt the benefits system to make it more responsive to individual carers' needs (Arksey, 2002; Yeandle *et al.*, 2002; Harper and Levin, 2005; Howard, 2005; Smith *et al.*, 2006; Bernard and Philips, 2007; Yeandle *et al.*, 2007c). In November 2010, the Government indicated in an updated National Carers Strategy (NCS) that it was "carefully considering" whether "changes to CA will be necessary" to take account of Universal Credit (HMG 2010). The NCS followed a call for evidence exercise in summer 2010 on views about future priorities in policy on carers. Among the key messages highlighted was the view that 'carers feel that the value of CA is inadequate, the rules around overlapping benefits are unfair, and the earnings limit is a disincentive to work' (HMG 2010: 6). This echoed views expressed previously in the 2008 NCS (HMG 2008) and in the House of Commons Work and Pensions Committee's report of its 2008 Inquiry on Carers (House of Commons Work and Pensions Committee (HoC WPC) 2008a). The latter asked the then Government (which did not make the requested changes) to consider replacing CA with a two-tiered benefit (a Carer Support Allowance and a Caring Costs payment). It also proposed changes to the rules on eligibility, the earnings disregard, the benefit's monetary value, and the status of CA² (WPC, 2008a). Similar issues had been noted in relation to the predecessor benefit Invalid Care Allowance (ICA) in a much earlier academic report published by the then Department of Health and Social Security (DHSS) (McLaughlin 1990).

² There is some ambiguity in the available evidence base about the status and purpose of CA (HoC WPC, 2008a). The DWP website describes CA as 'a taxable benefit to help people who look after someone who is disabled' (2010). CA is sometimes referred to as a 'contingent' benefit, as it can be claimed only by someone looking after a person in receipt of specified disability/sickness benefits. The official view is that CA is an 'income maintenance benefit'.

Carers are an extremely diverse group and a ‘fluid’ category. Every week, month and year new people become carers and some others’ caring responsibilities end (House of Commons Public Accounts Committee (HOC PAC), 2009). The level of care an individual carer provides varies according to the needs of the person they care for and the extent to which they have other support with their caring role: some have to give up work, while others manage to ‘juggle’ their multiple responsibilities (Phillips *et al.*, 2002). The 2001 Census showed that almost two million people were providing regular care for at least 20 hours per week, including 1.25 million people caring for 50 or more hours per week. Carers’ needs and experiences also vary according to their own circumstances. Older carers tend to be frailer and in poorer health than younger carers (Dahlberg *et al.*, 2007) and studies of carers around the world have highlighted that gender, ethnicity and cultural factors have implications for how caring is experienced (Jegermalm, 2006). A consistent thread running through the literature on carers is that financial and employment difficulties are particularly common, especially among those whose caring roles are very demanding.

2.2 Carer’s Allowance: key issues

CA is a state benefit intended to acknowledge the role of carers whose incomes have been affected by significant caring responsibilities and contribute to their financial support. In November 2009 it was paid to 526,620 people (Table 2.1).

For some years, CA has been subject to critical comment in the research and policy literature³, and to explore the issues raised, previous research on CA is briefly summarised to provide the context for the study. The history of Carer’s Allowance goes back to the introduction of ICA in 1975, and was summarised in the HoC WPC’s report *Valuing and Supporting Carers* (HoC WPC 2008a).

Table 2.1 Carer’s Allowance: claimants in payment by gender and age (November 2009)

| | Total | | Female | | Male | |
|-------------|---------|-----|---------|----|---------|----|
| | Number | % | Number | % | N | % |
| Total | 526,620 | 100 | 386,000 | 73 | 140,620 | 27 |
| Under 18 | 1,560 | 0 | 940 | 60 | 610 | 40 |
| 18-24 | 22,660 | 4 | 14,970 | 66 | 7,690 | 34 |
| 25-29 | 32,090 | 6 | 25,680 | 80 | 6,410 | 20 |
| 30-34 | 46,930 | 9 | 39,140 | 83 | 7,780 | 17 |
| 35-39 | 69,930 | 13 | 57,580 | 82 | 12,350 | 18 |
| 40-44 | 81,500 | 15 | 64,480 | 79 | 17,030 | 21 |
| 45-49 | 76,730 | 15 | 57,490 | 75 | 19,230 | 25 |
| 50-54 | 68,450 | 13 | 49,220 | 72 | 19,230 | 28 |
| 55-59 | 70,170 | 13 | 48,900 | 70 | 21,270 | 30 |
| 60-64 | 38,770 | 7 | 13,070 | 34 | 25,710 | 66 |
| 65 and over | 17,840 | 3 | 14,530 | 81 | 3,310 | 19 |

Source: Department for Work and Pensions.

³ Key issues were explored in the HoC WPC investigation (WPC, 2008b), with recommendations about CA presented in its report *Valuing and Supporting Carers* (WPC, 2008a).

Since 2003, CA has been available to carers who are: 16 years old or over and caring, for 35 or more hours per week, for a person who is in receipt of Disability Living Allowance (DLA), Attendance Allowance (AA) or Constant Attendance Allowance (CAA). CA claimants are allowed to earn up to £100 (2010-11 rate)⁴ from their paid employment without losing any of their CA (Directgov, 2010) and must not be in full-time education (more than 21 hours of supervised study a week). The 35 hours of care rule means that CA recipients are necessarily among those who dedicate the largest amount of time to their caring role. The rule making only those earning up to £100⁵ eligible for CA also means that anyone awarded CA cannot, assuming they are paid at or above National Minimum Wage (NMW), be in full-time paid work. Not all carers who would be entitled to claim CA do so, though there are no official figures available for those eligible carers who do not apply for the benefit and it is not known why they do not apply (National Audit Office (NAO), 2009).

Detailed figures for ('claimants in payment' (i.e. those carers who were both eligible to claim CA and who were assessed as entitled to receive a CA payment) are shown in Table 2.1. CA claimants in payment were (like all those eligible⁶), more likely to be female (386,000 women and 140,620 men). Approximately 20 per cent of CA claimants in payment were aged 18-34 years, with a further 70 per cent aged 35-59. Women outnumber men in all age bands except age 60-64.

The length of time CA claimants in payment had been receiving CA (in their current claim) is shown in Table 2.2. In November 2009, 39 per cent of CA claimants had been in receipt of CA (or ICA prior to 2003) for five or more years. More recent claimants (carers who had been receiving CA for less than one year) constituted 19 per cent of claimants. These figures are consistent with other evidence about carers (HoC PAC 2009), which shows that there is considerable movement in and out of caring, as well as a great deal of caring lasting for longer periods.

Table 2.2 Carer's Allowance: number of claimants in payment by gender and duration of current claim (November 2009)

| | All | Women | | Men | | Percentage duration |
|---------------------------|---------|---------|----|---------|----|---------------------|
| | | Number | % | Number | % | |
| Total | 526,620 | 386,000 | 73 | 140,620 | 27 | 100 |
| Up to 3 months | 20,180 | 13,350 | 66 | 6,830 | 34 | 4 |
| 3 months up to 6 months | 27,110 | 18,240 | 67 | 8,870 | 33 | 5 |
| 6 months up to 1 year | 50,130 | 34,240 | 68 | 15,890 | 32 | 10 |
| 1 year and up to 2 years | 78,650 | 56,410 | 72 | 22,240 | 28 | 15 |
| 2 years and up to 5 years | 144,920 | 106,930 | 74 | 37,990 | 26 | 28 |
| 5 years and over | 205,630 | 156,830 | 76 | 48,800 | 24 | 39 |

Source: Department for Work and Pensions.

⁴ The study reported here was conducted in 2009/10, immediately prior to April 2010, when the CA earnings limit was increased from £95 to £100. Quotations from a number of forum respondents and carer advisers in this report may include the lower figure, which was correct at the time of these interviews.

⁵ The figure of £100 is used for CA calculations after adjustments for certain taxes and expenses.

⁶ Official data on CA for November 2009 showed there were then 969,710 carers with recognised eligibility to claim CA, of whom, 646,900 were women and 322,810 were men. Of these, just over half (526,620) were 'claimants in payment'.

Some changes to carer benefits were made in the period between 2001 and 2010. Invalid Care Allowance was renamed Carer's Allowance in 2002⁷; small changes were made to carers' financial support in 2001 (adjustments to Income Support (IS) Carer Premium) and in 2003 (changes affecting carers on Pension Credit); and a National Insurance Carer's Credit was introduced from 2010⁸.

The academic and policy literature has indicated over a long period that some features of CA (and ICA before it) are problematic for carers. This was acknowledged in both the 2008 NCS and the 2010 update and by the HoC WPC in 2008.

2.3 Previous studies of carers receiving Carer's Allowance

Although a number of previous studies have investigated aspects of the situation of carers in receipt of CA (discussed in section 2.4), few studies conducted with carers have specifically addressed the needs, experiences and perspectives of CA customers. In light of this, selective reanalysis of data available from the CES (Carers, Employers and Services) study (Yeandle and Buckner, 2007⁹) was undertaken as part of the present research. The CES study included detailed interviews with 134 carers (selected from a total sample of 1,909 carers surveyed) about their attitudes to employment and services. Among these, 16 discussed their experiences as CA claimants in some detail (the characteristics of this sub-sample are shown in Table 2.3).

Among the issues which emerged from this reanalysed data were:

- (i) Most of the CES CA claimants reported that caring had had an adverse impact on their household finances; this principally arose from limited employment possibilities, though the costs associated with providing care were also mentioned by some. One carer claimed that she frequently found herself making sacrifices, as she had to spend significant sums to buy medical products not provided by the NHS.

'I would say that I get by now, I don't have extra money. I get by. It's very much about coping with the present.'

(Female carer, CES study)

Others said they were paying higher utility bills, spending more on petrol (to attend medical appointments, etc.) and/or buying special equipment or extra services to help with the care needed¹⁰.

- (ii) Some of the CES CA claimants reported significant changes to their family's lifestyle as a result of caring. One man, caring for his wife (suffering from depression) felt he was unable to give his two sons the attention he should, a situation about which he felt immense guilt. He noted that his household income was half what it had been ten years earlier (his household income, when interviewed, comprised DLA, IS, CA, and very limited earnings from paid work). Although he still had a job, he felt his ability to retain this was at serious risk, and mentioned that the rules for CA limited his earnings (at that time) to £300 a month, observing:

⁷ Regulatory Reform (Carer's Allowance) Order 2002, Statutory Instrument 1457 (change to S70 of the Social Security Contributions and Benefits Act 1992).

⁸ For every week that CA is paid, a National Insurance credit is awarded to protect claimants' State Pension. If carers are not entitled to CA, they can still protect their State Pension by claiming Carers Credit. This can be claimed for 20 hours of care or more, can be for more than one person they care for, and is also available to carers who care for someone not in receipt of DLA/AA.

⁹ The CES study produced a series of six reports, plus separate reports for Scotland, Wales and six English districts. Yeandle and Buckner 2007 summarises the study findings and includes references for all the other CES reports.

¹⁰ Disability Living Allowance, the qualifying benefit for people who are cared for by CA customers, is intended to help pay for such items, but some carers in the CES study nevertheless found they needed to 'top up' this expenditure.

'If you earn £300 a month, it's pretty nifty if you can pay a £100,000 mortgage on that.'

(Male carer, CES study)

Table 2.3 Carer's Allowance claimants, CES study sub-sample¹¹

| | Number |
|-----------------------------------|--------|
| Gender | |
| Male | 4 |
| Female | 12 |
| Age | |
| 16-24 | 1 |
| 25-34 | 2 |
| 35-49 | 6 |
| 50-59 | 3 |
| 60-64 | 4 |
| Person cared for | |
| Spouse/partner | 3 |
| Grandparent | 2 |
| Parent/parent-in-law | 9 |
| Child/grandchild (under 20) | 2 |
| Employment circumstances | |
| Looking after family/caring FT | 3 |
| FT paid work | 3 |
| PT (<30 hrs) paid work | 6 |
| Looking for work/unemployed | 1 |
| Permanently sick/disabled | 1 |
| (Early) retired from paid work | 1 |
| Student | 1 |
| Weekly amount of care | |
| 50+ hours | 11 |
| 35-49 hours | 3 |
| 1-34 hours | 2 |
| Health status | |
| Good | 5 |
| Fairly good, some health problems | 7 |
| Poor | 4 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

¹¹ Those in this sub-sample (16 carers) discussed CA directly. Some other CES interviewees (134 carers) may also have been in receipt of CA. The 16 carers referred to here were selected for interview for the CES study, which focused on carers and employment. This accounts for the fact that more than half these carers (nine out of 16) were in paid employment, which is higher than for CA customers generally (see Chapter 6). Two of the 16 carers referred to here had recently ceased to receive CA (those indicated as caring for 1-34 hours per week) but, during the interviews, reflected on their previous experiences as recipients of CA.

- (iii) Concern about limited opportunities to enter or remain in paid employment was a common theme for carers who had either given up paid work to care or who expressed a desire to return to work. As one put it:

'I could just go to work, find myself a job and earn ten times what I earn in a week. The thing is I can't, because I'm caring and everything.'

(Female carer, CES study)

- (iv) Some carers commented on facing challenges at work (arising from the complexities of care) and/or claimed that the eligibility rules for CA reduced the number of hours they could work. Some resented having to 'choose' between claiming CA or remaining in employment. One now worked only 12 hours per week:

'Otherwise I'd have to do over 20 hours just to earn the same. So it's not worth doing any more really. So that's why I do the 12. I did go back to do more, but it didn't work out, so that's why I had to reduce them [...] I didn't mind cutting down a bit, but, you know, I enjoy my work, it's a nice job. Financially we could have done with doing more hours.'

(Female carer, CES study)

- (v) Some expressed concerns about the way CA interacts with other benefits, particularly State Pension, noting that, because of the 'underlying entitlement' rules, once they reached retirement age they would not receive any CA payment. One claimed that CA recipients were 'discriminated against' in comparison to those receiving other benefits, such as Housing Benefit or Council Tax Benefit.

'Why should you lose it? I know you get a pension, which I've paid into – I did, for 17 years [...] Why should I lose that £40 a week because of my age?'

(Female carer, CES study)

- (vi) Among the CES CA sample, some felt the eligibility rules for CA were complicated, something they also thought true of other benefits of which they had experience. Some spoke about assisting the person they cared for to claim benefits, including those which are qualifying benefits for their own claim for CA. One noted the many difficulties she felt she had had in applying for AA on behalf of her grandmother; a process she had found complex, bureaucratic and time-consuming. A few criticised the length of time it takes to process a CA claim:

'It's taken me six months to get Carers' Allowance. Don't ask. Six months to get that! So I've been at £330, instead of £680, and they expect it not to affect your finances!'¹²

(Female carer, CES study)

The comments of this sub-sample of respondents to the CES survey in 2006/07 were broadly consistent with other perspectives on CA recorded in the existing literature and with the evidence given to the HoC WPC in 2008. However, like other available evidence, they were based on a small number of carers in a study not specifically designed to explore the situation and perspectives of CA customers. The new data presented in Chapters 3-7 of this report, collected from CA claimants selected from a sample of 1,600 DWP records, addresses this gap in previous research and offers a wider perspective on carers claiming CA, focusing on their caring, living and employment circumstances. Before turning to this new evidence, a brief summary of relevant themes in other past studies is presented to conclude the present chapter.

¹² It should be noted that the average clearance time for a CA claim is less than 14 days. The Carer's Allowance Unit (CAU) looks into claims that are a month old as a matter of urgency. A claim would not be allowed to continue for more than six months.

2.4 Perspectives on Carer's Allowance

A qualitative study carried out in 2007 by The Disability and Carers Service (DCS) found that many CA recipients see CA as a 'compensation' for their limited ability to work, arising from their caring role (Hawkins *et al.*, 2007). Those who believe CA is (or should be) an income replacement benefit (see above) tend to argue that CA is 'too low', as other such benefits are paid at a higher weekly rate (WPC, 2008a; Carers UK, 2008). Others view CA as a benefit which contributes to carers' foregone earnings when they have to give up, or reduce, their hours of work (NAO 2009). Earlier studies have shown, as does this report (Chapter 6), that most carers would prefer to combine their caring with paid employment. When outside paid employment, most carers do not consider themselves 'unemployed', and many feel CA and the benefits system in general should 'reward' them in some way for the care they provide (Arksey *et al.*, 2005; Yeandle *et al.* 2007b).

Carers who have an 'underlying' entitlement to CA, but who receive another benefit whose value is greater than the maximum CA payment permitted (such as State Pension), cannot receive any CA payment, although they retain some 'passported' benefits associated with CA. Carers who reach retirement age with entitlement to a State Pension find their CA payment is stopped when they reach this age, even though no other change has occurred, and their caring responsibilities continue. This also occurs because CA and State Pension are benefits designed to maintain earned income, and only one such benefit can be paid in respect of this. Where a carer is entitled to an income maintenance benefit which is payable at a higher rate than CA, a top-up of IS (known as a Carer Premium) can be paid to make up the difference. Pension Credit is awarded to pensioners on low incomes, and if CA is awarded to a Pension Credit recipient, they will receive a Carer Premium.

In 2009, a House of Commons Public Accounts Committee (HoC PAC) report noted that the regulations relating to CA had the effect of confusing service providers, as well as many carers, about the purpose of CA as a benefit (HoC PAC, 2009: 1). An NAO report made a similar point:

'...the circumstances and expectations of Carer's Allowance recipients vary widely and our interviews with carers and partners show that some carers have unmet expectations in terms of whether the Allowance is a wage for caring, a reward for caring, compensation for the costs of caring, or a reflection of the extent of care they provide.'

(NAO, 2009: 14)

It also noted: many carers' anger about what they perceive as the low 'wage' they are paid to care; a lack of awareness among carers that they may be eligible for state benefits in relation to the care they provide; and that carers often see their caring responsibilities as part of their role as a family member, rather than as 'caring'. The report suggested that carers' concerns about the lack of recognition they feel from society relate not only to the amount of CA they receive, but also to how they experience the rules about receiving CA alongside other benefits, a point which is further supported in the findings of this study (Chapter 4).

Previous research has raised other issues about the complexity of carers' lives, evidence of which is presented in the new findings of this study in Chapters 4-6. For example, because each claim for CA is linked to a single award of DLA, AA or Constant AA (to the person being cared for by the applicant) those who work together in caring for one person (e.g. two parents caring for their severely disabled child), must decide which of them will claim CA as both cannot do so. Previous studies have also noted that CA rules do not allow for carers who care for more than one sick or disabled person (if none of these people, individually, meets the criteria for CA in terms of their disability benefits) even if the total hours of care provided (to more than one person) is greater than 35 hours (HoC WPC, 2008a).

Earlier studies have reported a plethora of different sources of information on CA, with medical professionals, the internet, and various voluntary organisations (among others) being used for this. Jobcentre Plus, a key source of information on benefits for carers as for others, was criticised in one study because the level of knowledge about CA among its staff was inadequate (Hawkins *et al.*, 2007). Similar experiences were found in the present study and are discussed in Chapter 4.

2.5 Carers and paid employment: implications for Carer's Allowance

In addition to previous research and investigations on carers and CA, a number of studies have focused on carers and paid employment, in some cases highlighting the situation of those claiming CA. This section discusses this earlier evidence of the importance of paid work to carers, of how the rules relating to CA impact upon carers' capacity to seek paid employment, and about how difficult it can be for carers to combine their caring responsibilities with a paid job.

2.5.1 Carers and paid employment

The 2001 Census showed that, among carers of working age, 1.5 million were in full-time employment and some 675,000 were in part-time work; a further 131,000 carers were unemployed and actively looking for work. The effect of caring on an individual's working life increases with the amount of hours of care they provide (Yeandle *et al.*, 2007a). Those caring for more than 20 hours per week were significantly more likely to live in workless households; and the more hours of care a carer gives, the greater their chance of giving up work (HMG, 2008). Among people caring for over 50 hours a week, 59 per cent reported giving up work to care, while a further 18 per cent had reduced their working hours (Carers UK, 2008).

A longitudinal study (2002-05) of parents caring for a sick or disabled child found that most felt caring had had an adverse impact on their paid employment (Stiell *et al.*, 2006). These carers cited stress, tiredness and the difficulties of having to take time off as significant problems. Of those who responded to the second wave of the study, 65 per cent believed their caring responsibilities had a negative impact on their career development, and over 61 per cent had needed to take time off from work to accommodate their caring role.

Another study analysed survey data on 400 carers aged under 65 who had given up work to care, finding that, compared with other carers, they were the most likely to report financial difficulties and to be in poor health (Yeandle *et al.*, 2007b).

It is clear that some carers outside the labour market wish to engage in paid work; the NAO found that about a quarter of the 7,000 carers in its study wished to combine their caring with paid work (2009: 10). In a study of 1,127 carers of disabled children, 370 (66 per cent) of those not currently in paid work (n= 586) expressed a desire to return to employment (Stiell *et al.*, 2006). The CES study (2007) found that 55 per cent of 701 carers of working age who were outside paid employment said they would rather be in paid work than caring full-time, 69 per cent reporting that their caring situation 'led to me leaving paid work' (Yeandle *et al.*, 2007b: 28).

In the recent past, official policy has repeatedly identified employment as the most sustainable way to ensure that carers' financial needs are met. Consistent with this, the 2008 NCS stated that,

'While the benefits system can provide a safety net, the most reliable and sustainable means of ensuring that carers can enjoy a reasonable level of income is if they, where possible, combine paid employment with their caring role.'

(2008: 85)

The NAO (2009) subsequently noted that, of the 883,000 people then eligible for CA (i.e. caring over 35 hours a week), only one in ten were currently combining caring with paid employment. Paid work is important for carers' for financial, social and health reasons. Research by Carers UK, presented in evidence to the HoC WPC, indicated that, on average, carers lose *'£11,000 each year as a result of giving up work, reducing their hours or taking a more junior position'* (HoC WPC, 2008b: Ev141), and that carers consistently face additional costs that DLA and AA do not cover (HoC WPC, 2008a). Many carers report significant psycho-social benefits of continuing in employment too. In one study, a respondent claimed:

'[Work means] sanity. If I constantly stay in and have my life being revolved around the children and the house I think I'd go mad. [Work] brings out the creativity in my mind...I feel that I've found my niche and I'd really hate to lose it, but I've always been a carer...and I just wanted to be myself...and I am myself when I'm studying or when I'm at work.'

(Stiell et al., 2006: 8)

Vickerstaff et al. (2009) also noted that paid work can play an important role in providing structure in carers' daily lives, a much-valued connection to the social world, a break from caring and a way to bolster carers' self-esteem. Other (comparative and international) evidence indicates that carers forced into poverty and low socio-economic activity by their caring responsibilities suffer poorer health (Farfan-Portet et al., 2009), a point also evidenced in analysis of the 2001 Census (Buckner and Yeandle, 2006).

2.5.2 Carer's Allowance and paid employment

Despite some policy developments designed to encourage carers to remain in employment (e.g. the Work and Families Act 2006), the work-related rules for CA appear to discourage them from seeking or remaining in employment (HoC WPC, 2008a). The limit on earnings makes those with higher incomes from paid work ineligible for CA. NMW levels mean that most carers in receipt of CA can only work up to 17 hours per week (fewer if they earn more than the NMW), as the NMW for most earners is £5.80 per hour (the rate from 1 October 2009¹³) and the maximum earnings limit for CA is £100 (increased from £95 in April 2010), acting as a disincentive to remaining in the workforce for many carers. CA also affects some carers' ability to engage in paid work by limiting their access to training or education. At present, carers studying for more than 21 hours per week are ineligible for CA (because it would be difficult to combine this with caring for at least 35 hours per week). It has been suggested that this acts as a disincentive to engage in full-time training or study and may make it hard for some carers to qualify for, or find, suitable work (HoC WPC, 2008a: 49-50). Findings from the present study support these points and are discussed in Chapter 6.

¹³ This rate applies to people over 22 years old. A 'development rate' of £4.83 per hour applies for workers aged 18-21 inclusive, and the rate is £3.57 per hour for workers under the age of 18 who are no longer of compulsory school age. Anyone 16 years or over is eligible to claim CA, so these lower wage figures would, in accordance with the £100 earnings limit, allow for more hours of employment than stated here for carers under age 23.

A previous report for DWP, *Carers' aspirations and decisions around work and retirement* (Arksey et al., 2005), included exploration of the situation of 28 carers in receipt of CA and found:

- those who were working tended to be in low paid employment (especially women), sometimes took jobs below their skill levels and often found it difficult to tailor working hours to meet the eligibility criteria for CA;
- some carers who were not working said their decision to apply for CA had involved leaving paid employment, even though they were not certain their CA application would be successful;
- when seeking paid employment, non-working carers were worried about whether they would still qualify for CA (and other benefits, such as IS and Housing Benefit);
- for many carers, the study concluded, *'it was a case of full-time work or no work at all because the scope for working whilst receiving CA was too limited'* (Arksey et al., 2005: 114).

Similar observations were made in a separate study of carers of disabled children, which found that in trying to combine caring with work, or to return to work after a period of economic inactivity, carers faced several problems. Some found that their skills had become out of date; others felt that having been out of contact with the job market, they lacked adequate connections to individuals, organisations or support services. Carers in this study felt caught in a benefits trap, which reduced motivation and confidence for some. Others pointed out that gaps in a carer's CV could be difficult to explain to prospective employers (Stiell et al., 2006).

All of these issues were reflected in the findings of the present study and are discussed in Chapter 6.

3 About the study

Data was collected for the new study of Carer's Allowance (CA) customers, the main focus of this report, between October 2009 and June 2010, using a mixed methods approach. The methods used included:

- interviews with carer advisors specialising in CA claimants;
- a postal survey of CA claimants (just over 500 completed questionnaires);
- eight group discussions with CA claimants in four localities;
- individual interviews with a subsample of CA claimants drawn from the survey respondents.

3.1 Stage one

The study began with a review of recent government, academic and independent sector research and studies relating to carers and CA to provide a background and context for the study and inform the research design and instruments.

Telephone interviews were conducted with 11 representatives of organisations which provide support to CA customers (Appendices A and B.1), and a discussion forum was also conducted with ten staff members in the DWP's Carers Allowance Unit (CAU) (Appendix B.2). A telephone interview was also conducted with a staff member at the CAU who dealt with carer appeals against unsuccessful CA applications (Appendix B.3).

3.2 Stage two

Drawing on the information collected in stage one of the research, new research instruments were designed to facilitate data collection with carers. A structured questionnaire (Appendix B.4) was distributed to 1,600 CA customers. The questionnaire collected detailed information about CA customers and their caring situation and circumstances, including information about their employment, qualifications, health and finances (including the way their CA payment was spent). The questionnaire was sent to a total of 1,600 carers, with usable responses received from 504 carers.

3.3 Stage three

Eight carer discussion forums¹⁴ were conducted, two in each of the four locations selected, one in London, two in areas in the north of England, and one in Scotland. Each forum was attended by between nine and 11 participants, all of whom were carers receiving CA, and was held in a venue arranged by the research team. The forums were themed according to eight different kinds of carer characteristics, identified in the literature review as relevant in studying CA claimants (Appendix A). The topic guide (Appendix B.5) was designed on the basis of information from the literature review and the carer adviser interviews.

¹⁴ Participants from each forum will be referred to in this report by their gender and the theme of the forum in which they participated. The theme codes for all of the forums are included in Appendix A.

The telephone interviews (n=10) were carried out with CA claimants using a topic guide (Appendix B.6) designed to focus on issues raised or indicated in the forums, but which necessitated research contact at an individual rather than a group level (e.g. financial or personal matters), which forum members may not have wished to share or divulge in a group setting.

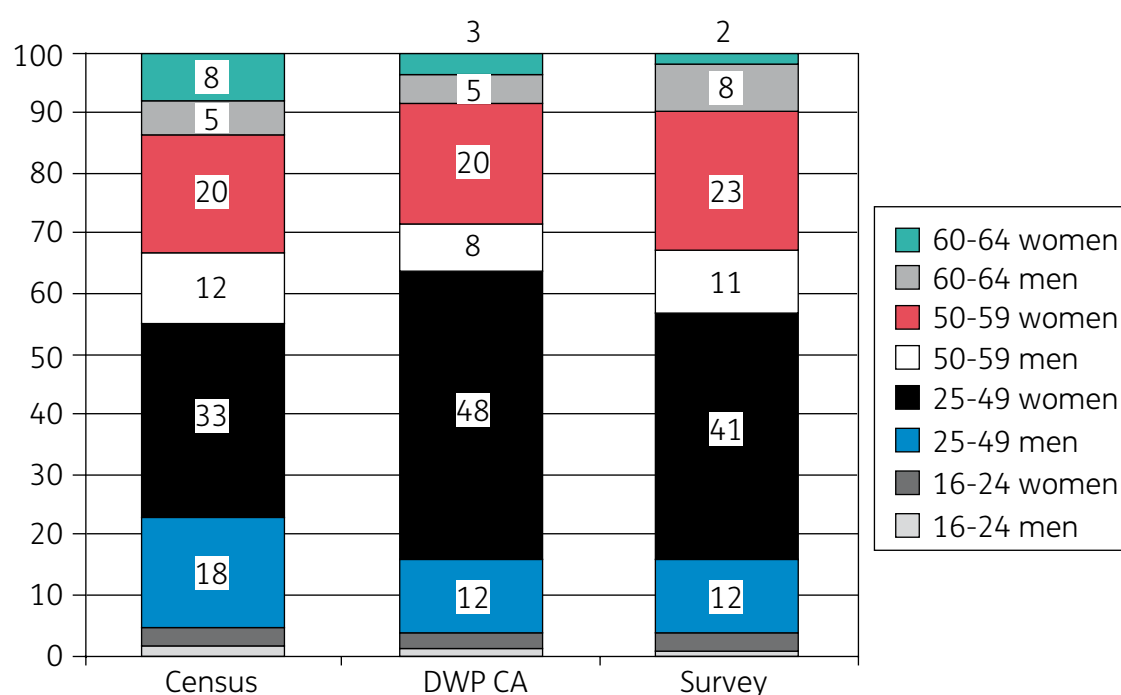
Data from the study provided detailed survey information about 504 CA customers, and allowed for nuanced detail to emerge in the qualitative stages of the research, in which 83 individual CA customers participated. The data in this report was not designed to be fully representative of all CA claimants in the UK, but the survey respondents share many characteristics with the wider CA customer group, and with the general population of carers of working age (see the discussion in Chapter 4). As such, it offers considerable insight into the history, experiences, everyday lives and future plans of a large group of carers in receipt of this benefit, and provides a good indication of the circumstances, contexts, backgrounds and perspectives relevant to this group of carers and to the situation of carers of working age more generally.

4 Carers claiming Carer's Allowance: contexts and pathways

This chapter presents a profile of the Carer's Allowance (CA) customers who participated in the study, before exploring issues relating to the benefits they receive, including, or in addition to, CA, and discussing how carers came to claim CA, the choices they make and constraints they encounter, and some issues raised spontaneously by research participants relating to the CA application process. Where possible, information about CA customers in the study is compared with data on other carers receiving CA in the UK, and with carers in general.

4.1 General characteristics of Carer's Allowance customers

The survey of CA claimants in this study used a questionnaire focused on a range of carer characteristics and issues relating to the care they provide, discussed in Chapters 4 to 6 of this report. The survey was designed to explore key issues identified in previous research on CA claimants (Chapter 2); questions on some other aspects of their lives were included to cover issues of particular interest to the Department for Work and Pensions (DWP). A summary of some of the personal characteristics of the respondents is presented in Table 4.1, and in Figure 4.1 carers in the survey are compared (on the variables gender and age) with data on carers in DWP claimant data (national level, all claimants in August 2009), and in the 2001 Census, which covered the whole population.

Figure 4.1 Carers by age and gender: Census, DWP claimant data and CA survey compared

Source: 2001 Census SAM, DWP CA data supplied by DWP, Survey of Carer's Allowance customers, CIRCLE, University of Leeds, 2010.

Carers in the CA survey were mostly female (69 per cent), aged 35-59 (72 per cent), white British (79 per cent) and people with no, or very modest levels of, formal educational qualifications. Although these survey respondents are not statistically representative of all CA claimants, the comparisons of some of their characteristics with Census and DWP official data shown in Figure 4.1 and Table 4.2 show the CA survey respondents are nonetheless quite similar in some respects to the carers captured in these other sources. The survey data include slightly fewer 25-49 year old women, and slightly more 50-59 year old women, and (compared with 2001 Census data on all carers) in both the datasets relating to CA customers, there are considerably more women aged 25-49 years and considerably fewer men of this age. Further analysis revealed that, compared with data on carers aged 16-64 from the 2001 Census (caring for 20+ hours per week), carers in the CA survey:

- were more likely to be from a Black and Minority Ethnic (BAME) group (79 per cent of carers aged 16-65 in the survey were White British, compared with 88 per cent of carers in the 2001 Census);
- were more likely to describe their health as 'not good' (27 per cent compared with 16 per cent);
- had a similar qualifications profile:
 - 45 per cent of carers with no qualifications, compared with 42 per cent;
 - 45 per cent with qualifications below degree level, compared with 46 per cent;
 - 10 per cent with degree qualifications or above, compared with 12 per cent.

Table 4.1 CA survey respondents: selected characteristics

| Characteristic | All carers | | Carers* of a: | | | | | |
|-------------------------|------------|-----|-------------------|-----|-------------------------|-----|---------------------|-----|
| | | | Spouse or partner | | Parent or parent-in-law | | Child or grandchild | |
| | Number | % | Number | % | Number | % | Number | % |
| Gender | 486 | 100 | 123 | 100 | 120 | 100 | 185 | 100 |
| Male | 151 | 31 | 69 | 56 | 43 | 36 | 22 | 12 |
| Female | 335 | 69 | 54 | 44 | 77 | 34 | 163 | 88 |
| Age | 497 | 100 | 128 | 100 | 123 | 100 | 185 | 100 |
| 16-24 | 17 | 3 | 0 | 0 | 9 | 7 | 5 | 3 |
| 25-34 | 55 | 11 | 9 | 7 | 11 | 9 | 28 | 15 |
| 35-49 | 194 | 39 | 29 | 23 | 50 | 41 | 93 | 50 |
| 50-59 | 166 | 33 | 46 | 36 | 45 | 37 | 52 | 28 |
| 60-64 | 48 | 10 | 32 | 25 | 7 | 6 | 4 | 2 |
| 65+ | 17 | 3 | 12 | 9 | 1 | 1 | 3 | 2 |
| Ethnicity – all | 498 | 100 | 128 | 100 | 123 | 100 | 186 | 100 |
| White British | 392 | 79 | 109 | 85 | 97 | 79 | 143 | 77 |
| White other | 7 | 1 | 3 | 2 | 2 | 2 | 2 | 1 |
| White other | 10 | 2 | 3 | 2 | 3 | 2 | 2 | 1 |
| All mixed ethnic groups | 11 | 2 | 3 | 2 | 1 | 1 | 4 | 2 |
| Indian | 4 | 1 | 2 | 2 | 1 | 1 | 0 | 0 |
| Pakistani | 14 | 3 | 1 | 1 | 4 | 3 | 7 | 4 |
| Bangladeshi | 5 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| Black Caribbean | 18 | 4 | 0 | 0 | 7 | 6 | 8 | 4 |
| Black African | 20 | 4 | 2 | 2 | 3 | 2 | 13 | 7 |
| All other ethnicities | 17 | 3 | 4 | 3 | 4 | 3 | 6 | 3 |
| Education – all | 470 | 100 | 114 | 100 | 119 | 100 | 177 | 100 |
| No qualifications | 216 | 46 | 60 | 53 | 55 | 43 | 70 | 40 |
| Vocational only | 59 | 13 | 15 | 13 | 16 | 13 | 30 | 11 |
| Up to GCSE | 103 | 22 | 22 | 19 | 28 | 23 | 42 | 24 |
| Up to A level | 46 | 10 | 11 | 10 | 7 | 6 | 22 | 12 |
| Degree level or above | 46 | 10 | 6 | 5 | 13 | 11 | 23 | 13 |

Source: Survey of Carer's Allowance customers, CIRCLE, University of Leeds, 2010.

* Some respondents were carers in other categories, not shown here – see Table 4.3. Note: percentage figures are for respondents who answered the relevant question. They do not always add to totals because of missing data/rounding of percentages.

Table 4.2 Comparison of carers' characteristics: 2001 Census, DWP CA claimant data, and CA survey

| | 2001 Census (carers 20+ hours) | | | DWP CA data (carers receiving CA) | | | CA Survey (sample n=504) | | |
|---------------|-----------------------------------|-------|-----|--------------------------------------|-------|-----|-----------------------------|-------|-----|
| | Men | Women | All | Men | Women | All | Men | Women | All |
| Age | | | | | | | | | |
| 16-24 | 2 | 3 | 5 | 1 | 3 | 4 | 1 | 3 | 4 |
| 25-49 | 18 | 33 | 50 | 12 | 48 | 60 | 12 | 41 | 53 |
| 50-59 | 12 | 20 | 31 | 8 | 20 | 28 | 11 | 23 | 34 |
| 60-64 | 5 | 8 | 13 | 5 | 3 | 9 | 8 | 2 | 9 |
| All | 37 | 63 | 100 | 26 | 74 | 100 | 31 | 69 | 100 |
| In employment | 52 | 39 | 44 | 5 | 12 | 10 | 4 | 12 | 9 |
| Co-resident | 82 | 77 | 79 | 63 | 66 | 65 | 88 | 86 | 87 |

Source: 2001 Census SAM, DWP CA data 2009, Survey of Carer's Allowance customers, CIRCLE, University of Leeds, 2010.

4.1.1 Gender and age

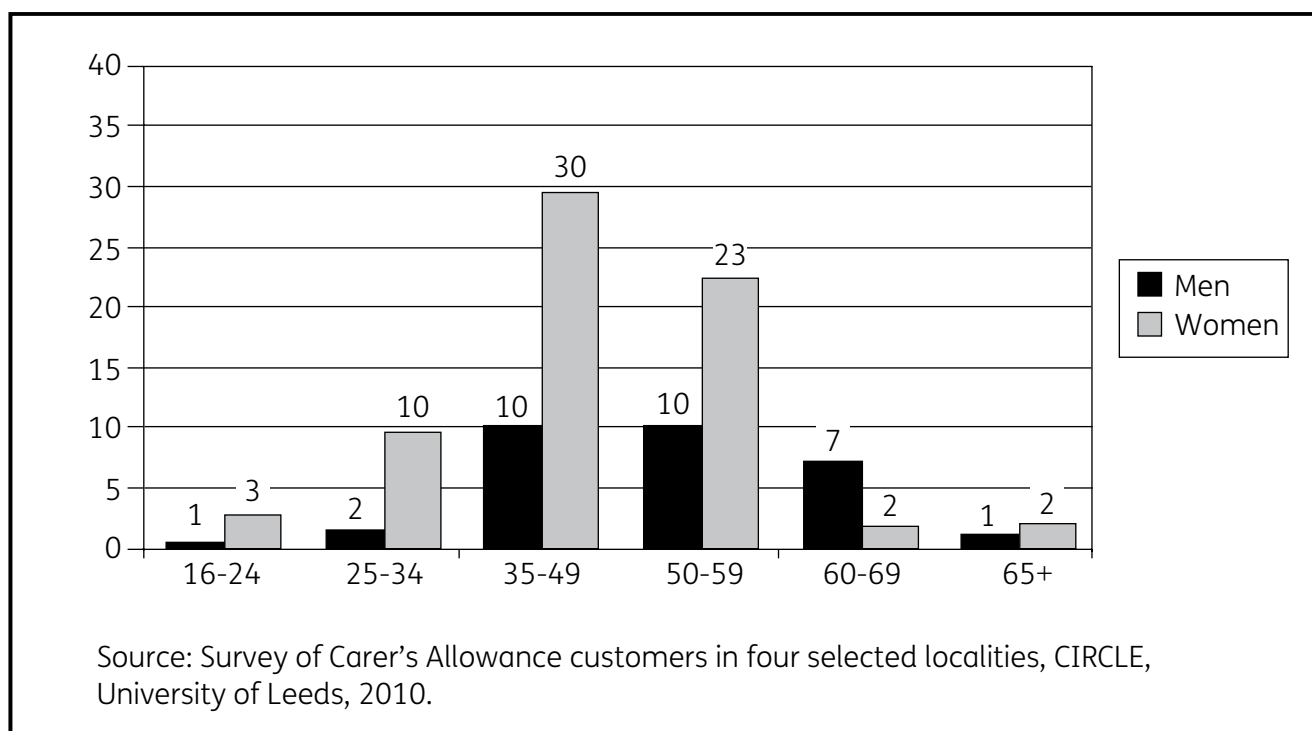
As seen in Tables 4.1 and 4.2, of the 504 respondents to the survey of CA customers in the four selected localities, just over two-thirds (69 per cent) were women and 31 per cent were men¹⁵. Most carers taking part in the discussion forums were also women (55 out of 73) and eight of the ten individual interviews were with women. Respondents in the forums and interviews raised a few issues which appeared to affect men and women differently. For example, one male carer caring full-time for his sick child felt other parents of children at his son's school expected him to have a job alongside his caring role; he felt guilt as a consequence of this impression, speculating that this might be a particularly 'male' response to being a full-time carer. A female carer felt the formal care services and support available (including CA) pre-supposed that a carer would have a partner with an income; she claimed that single parents, especially women, were particularly disadvantaged because they provided care on their own in a context of limited services and support.

The share of survey respondents aged between 25 and 49 (53 per cent), compares with 60 per cent for all CA customers at national level (Table 4.2). CA customers in the survey were a little more likely to be in the 25-49 age group than similar carers (those caring 20+ hours per week¹⁶) recorded in the 2001 Census (50 per cent).

Comparison of the survey with DWP national data also shows that slightly more of the survey respondents were men (31 per cent compared with 26 per cent), especially men aged 50+, and that the share of women aged 25-49 was lower in the survey (Table 4.2).

¹⁵ 18 respondents (four per cent) did not state their gender.

¹⁶ The 2001 Census collected data about weekly hours of care in three categories: 1-19, 20-49 and 50+ hours.

Figure 4.2 CA survey: respondents, by age and gender

The age/gender distribution of the survey respondents is depicted in Figure 4.2, showing that female survey respondents outnumbered male in all but the 60-64 age group (Figure 4.2).

Table 4.3 CA survey respondents, by age: selected characteristics

| | Carers' age | | | |
|---|-------------|---------|--------|---------|
| | 16-34 | 35-59 | 60+ | ALL |
| Employment status (p<0.001***) | (n=69) | (n=350) | (n=63) | (n=482) |
| Employed full-time | 5.8 | 9.7 | 0.0 | 7.9 |
| Employed part-time | 1.4 | 1.1 | 0.0 | 1.0 |
| Looking for work/unemployed | 2.9 | 4.3 | 1.6 | 3.7 |
| Student | 2.9 | 2.0 | 0.0 | 1.9 |
| Retired | 0.0 | 2.0 | 36.5 | 6.2 |
| Permanently sick/disabled | 1.4 | 2.0 | 7.9 | 2.7 |
| Looking after home/family/caring full-time | 84.1 | 74.6 | 52.4 | 73.0 |
| Other | 1.4 | 4.3 | 1.6 | 3.5 |
| Would prefer to be in paid work (p=0.804) | (n=56) | (n=269) | (n=36) | (n=361) |
| Those not currently in paid work only | 23.2 | 24.2 | 19.4 | 23.5 |
| Finding it difficult or very difficult to manage financially (p=0.528) | (n=70) | (n=359) | (n=65) | (n=494) |
| | 40.0 | 41.2 | 33.8 | 40.1 |
| In poor health (p=0.026*) | (n=72) | (n=357) | (n=65) | (n=494) |
| | 13.9 | 29.1 | 24.6 | 26.3 |
| Person cared for... (p<0.001***) – main recipient only | (n=70) | (n=349) | (n=64) | (n=483) |
| Spouse/partner | 12.9 | 21.5 | 68.8 | 26.5 |
| Grandparent | 4.3 | 0.9 | 0.0 | 1.2 |
| Adult child (over 20) | 1.4 | 10.3 | 6.3 | 8.5 |
| Other relative/family member | 4.3 | 7.2 | 4.7 | 6.4 |
| Parent/parent-in-law | 24.3 | 26.4 | 12.5 | 24.2 |
| Child/grandchild (under 20) | 45.7 | 31.2 | 4.7 | 29.8 |
| Friend/neighbour | 4.3 | 2.3 | 3.1 | 2.7 |
| Other | 2.9 | 0.3 | 0.0 | 0.6 |
| Length of time caring (p=0.011*) | (n=69) | (n=343) | (n=64) | (n=476) |
| Up to 6 months | 2.9 | 0.9 | 1.6 | 1.3 |
| From 6 months up to 1 year | 2.9 | 2.0 | 1.6 | 2.1 |
| One year up to 2 years | 10.1 | 6.1 | 7.8 | 6.9 |
| 2 years up to 5 years | 34.8 | 19.0 | 25.0 | 22.1 |
| 5 years up to 10 years | 34.8 | 29.7 | 28.1 | 30.3 |
| 10 years or over | 14.5 | 42.3 | 35.9 | 37.4 |
| Main use of Carer's Allowance (p=0.027*) | (n=65) | (n=334) | (n=60) | (n=459) |
| Regular care expenses | 18.5 | 16.5 | 16.7 | 16.8 |
| Emergencies | 4.6 | 2.4 | 1.7 | 2.6 |
| Travel costs | 13.8 | 6.9 | 3.3 | 7.4 |
| Holidays/breaks | 3.1 | 0.6 | 5.0 | 1.5 |
| Weekly income/general household expenses | 60.0 | 72.8 | 70.0 | 70.6 |
| Recreation/social activities | 0.0 | 0.9 | 1.7 | 0.9 |
| Cover costs of caring when ill | 0.0 | 0.0 | 1.7 | 0.2 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

A result is 'statistically significant' if it is unlikely to have occurred by chance. The most common significance level to show that a finding can be supported is 5 per cent (reported as p=0.05 or any figure below 0.05). This means that there is a 5 per cent or lower chance of the observed data occurring by chance (Young and Bolton, 2009).

The CA survey data for those respondents who answered selected questions is shown in Table 4.3. Overall, the survey respondents were strongly concentrated in the 'looking after home and family/caring full-time' group (73 per cent). Among all survey respondents:

- 24 per cent (among those not currently in paid work) would prefer to be working;
- 40 per cent were finding it 'difficult' or 'very difficult' to manage financially;
- 26 per cent were in poor health;
- 27 per cent were caring for a spouse or partner, 24 per cent for a parent, and 30 per cent for a sick or disabled child/grandchild;
- 68 per cent had been caring for five years or more; and
- 71 per cent were spending their CA on general weekly expenses, 17 per cent on regular care expenses, and seven per cent on travel costs.

Further analysis of their responses showed that:

- working age carers (16-59), when compared with older respondents, were:
 - more likely to be looking after their home/family or caring full-time;
 - more likely to report financial difficulties;
 - more likely to be caring for a child under 20 or for a parent;
 - more likely to be spending their CA on travel costs;
 - less likely to be caring for a spouse or partner;
- younger carers (16-34), compared with all older carers, were:
 - less likely to be in poor health;
 - more likely to be newer to caring;
- carers aged 35-59 years, compared with other age groups, were:
 - more likely to be in paid full-time employment;
 - more likely to be seeking paid employment;
 - more likely to be caring for an adult child;
 - more likely to have been caring for over ten years;
 - less likely to use CA to pay for holidays/breaks.

In the discussion forums and interviews¹⁷, most participants were aged 45-64. While younger carers took part, they tended to be less vocal than older carers, although some had a good deal to say about their caring experiences. Points made in the forum discussions about age included that being a younger carer:

¹⁷ 83 carers took part in the forums. In describing their responses, the following usage has been adopted: 'a few' is used when only a small number of respondents raised the issues mentioned; 'some' refers to more than 'a few' but not more than half of respondents; 'most' is used when more than half of carers shared a common view, or where there was a general consensus among respondents.

- was especially demanding, because younger carers faced a longer period living on a low income/benefits;
- made it very difficult for younger carers to build a career;
- made establishing a household, and long-term financial security, very difficult.

This view was shared by some older carers, including one forum participant who considered that the demands associated with caring roles and the financial constraints involved (including those relating to eligibility for CA) were especially difficult and frustrating for a younger person, because they were likely to be foregoing other prospects and opportunities.

Forum participants (including older people reflecting on the situation of younger carers) were concerned that younger carers could become locked in a 'cycle of dependency' on state benefits, with potential damage to their future prospects. Several pointed out that younger carers were likely to be supporting whole families, often providing care for a sick or disabled child, possibly a child with a condition which had been diagnosed at, or around, birth.

Younger carers were more likely than older carers to refer to the care they provided as a duty arising from their relationship with the cared for person, often their child. Some younger carers said they felt 'guilty' about receiving a state benefit for a role which fell to them as a matter of obligation. However, those who had reached a crisis in their caring situation pointed out that, when their caring role became so complex and demanding that holding down a job was very difficult or impossible, they had been forced to accept that there was no alternative to applying for this kind of financial assistance, despite their reservations about doing so.

Older carers, by contrast, were more likely to claim that the care they provided made a significant contribution to society, and to feel that the state benefits they received for caring were their just reward for this. In the discussion forums, older carers were particularly concerned about the fact that CA would no longer be paid to them once they reached State Pension age. Most felt this was grossly unfair, as their care would not end at this point, and was often expected to be more demanding as both the carer and the cared for person aged, possibly facing additional health problems associated with old age.

Apart from those new to caring, older carers¹⁸ in the study had learned, by experience, how to negotiate the various systems of support and services available to them, although they emphasised that their caring role was often compromised by a lack of time and energy to fight for the services they needed. Having provided care long-term, some older carers felt dispirited and exhausted and felt carers in general were largely unappreciated and misunderstood by society at large.

4.1.2 Ethnicity

Most respondents described themselves as White British (79 per cent). 101 carers from other ethnic groups also responded to the survey (three to four per cent of respondents were in the black African, Black Caribbean and Pakistani groups (Table 4.1)).

Participants in the forums included carers from white Irish, black Caribbean, Indian, Pakistani and 'Other ethnic' backgrounds, and two of the ten individual interviews were with carers of minority ethnic background. Their contributions in the forums and interviews did not highlight particular issues or problems relating to their caring roles or to claiming CA which were experienced only by

¹⁸ When used in relation to forum and interview participants, 'older carer' means those aged between 50 and 65. As all respondents were 'CA claimants in payment' issues for (and benefits received by) carers above State Pension age are not discussed in this research.

those in their ethnic group. However, several suggested that particular kinds of services are useful to carers of minority ethnic background, as they are sensitive to the needs of their particular culture (some reporting positive experiences of support services designed for carers and/or disabled people in BAME groups). Carer advisers contributing to the study noted that they occasionally received enquiries from carers whose first language was not English, and that translation/interpretation was sometimes a problem for carers claiming CA.

4.1.3 Education status

The level of education of the CA survey respondents was outlined in Table 4.1, showing that almost half of respondents (46 per cent) had no qualifications at all and that a further 22 per cent had qualifications at or below GCSE level only. However, one in eight respondents had some kind of vocational qualification, and one in five had A level or university degree level qualifications (approximately ten per cent in each case). This picture was broadly the same for both men and women in the study.

More detailed analysis of the circumstances of the CA survey respondents, comparing those who had higher level qualifications with all others in the survey, is presented in Table 4.4. This shows that, when compared with those with fewer qualifications, highly qualified carers in the survey were more likely to:

- be in full-time paid employment (11.4 per cent, compared with 7.1 per cent)
- be a student (6.8 per cent, compared with 0.8 per cent);
- be 'retired' (8.0 per cent, compared with 4.6 per cent);
- be caring for a child (under 20) (41.6 per cent, compared with 28.6 per cent); and
- say they would prefer to be in paid work (33.3 per cent, compared with 21.5 per cent).

It also showed that highly qualified carers were less likely to be:

- in part-time paid employment (0.0 per cent, compared with 1.4 per cent);
- looking after the home/caring full-time (61.4 per cent, compared with 76.6 per cent);
- caring for a spouse/partner (19.1 per cent, compared with 26.4 per cent);
- using CA for travel costs (3.6 per cent, compared with 8.0 per cent); and
- using CA for recreational/social activities (2.4 per cent, compared with 0.6 per cent)

Several carers in the forums suggested that, even with a high level of qualification, it was not always possible to get a job which made good use of this. One respondent had a university degree but had found the complexities of her caring role, combined with the rules for CA, restricted her to low-level part-time work for which her academic training was unnecessary.

Respondents in the forums were critical of the rule relating to study for CA customers (those studying for 21 hours per week or more are ineligible for CA). They felt this deterred some carers from accessing higher education courses, a point of particular interest given that many respondents described aspirations to have 'a life of their own' outside of caring, and that this frequently involved a desire to learn a new skill or enter a new profession, through some type of educational course. Some talked about hoping, once their caring role had ended or had grown more manageable, to seek a formal qualification to facilitate return to the job market. Many also reported that, at present, the complexity and unpredictability of the care they provided was not conducive to study, which they would find difficult even if the work could be organised in a flexible way (e.g. home-based study). Study was commonly regarded as something which required a good deal of focus and concentration, and care situations were often described as involving insurmountable distractions.

The discussion in Section 4.1 has introduced the study sample and its characteristics. In the remainder of this chapter, and in Chapters 4 and 5, the focus is on other dimensions of these carers' lives, beginning with their access to welfare benefits and services.

Table 4.4 CA survey respondents: selected characteristics, by level of qualification

| | Carers' qualifications | | All |
|--|------------------------|-------------------|---------|
| | None or below A level | A level and above | |
| Employment status (p=0.004**) | (n=367) | (n=88) | (n=455) |
| Employed full-time | 7.1 | 11.4 | 7.9 |
| Employed part-time | 1.4 | 0.0 | 1.1 |
| Looking for work/unemployed | 3.3 | 5.7 | 3.7 |
| Student | 0.8 | 6.8 | 2.0 |
| Retired | 4.6 | 8.0 | 5.3 |
| Permanently sick/disabled | 2.5 | 3.4 | 2.6 |
| Looking after home/family/caring full-time | 76.6 | 61.4 | 73.6 |
| Other | 3.8 | 3.4 | 3.7 |
| Would prefer to be in paid work (p=0.042*) – people not currently working | (n=284) | (n=69) | (n=353) |
| | 21.5 | 33.3 | 23.8 |
| Finding it difficult or very difficult to manage financially (p=0.425) | (n=374) | (n=92) | (n=466) |
| | 40.9 | 39.1 | 40.6 |
| In poor health (p=0.345) | (n=378) | (n=90) | (n=468) |
| | 26.2 | 28.9 | 26.7 |
| Person cared for... (p=0.259) | (n=367) | (n=89) | (n=456) |
| Spouse/partner | 26.4 | 19.1 | 25.0 |
| Grandparent | 1.6 | 0.0 | 1.3 |
| Adult child (over 20) | 7.4 | 9.0 | 7.7 |
| Other relative/family member | 7.1 | 4.5 | 6.6 |
| Parent/parent-in-law | 25.3 | 22.5 | 24.8 |
| Child/grandchild (under 20) | 28.6 | 41.6 | 31.1 |
| Friend/neighbour | 2.7 | 3.4 | 2.9 |
| Other | 0.8 | 0.0 | 0.7 |
| Use of Carer's Allowance (p=0.042*) | (n=351) | (n=84) | (n=435) |
| Regular care expenses | 16.2 | 17.9 | 16.6 |
| Emergencies | 3.1 | 0.0 | 2.5 |
| Travel costs | 8.0 | 3.6 | 7.1 |
| Holidays/breaks | 2.0 | 0.0 | 1.6 |
| Weekly income/general household expenses | 70.1 | 75.0 | 71.0 |
| Recreation/social activities | 0.6 | 2.4 | 0.9 |
| Cover costs of caring | 0.0 | 1.2 | 0.2 |

Source: Survey of Carer's Allowance customers, CIRCLE, University of Leeds, 2010.

It also showed that highly qualified carers were less likely to be:

- in part-time paid employment (0.0 per cent, compared with 1.4 per cent);
- looking after the home/caring full-time (61.4 per cent, compared with 76.6 per cent);
- caring for a spouse/partner (19.1 per cent, compared with 26.4 per cent);
- using CA for travel costs (3.6 per cent, compared with 8.0 per cent); and
- using CA for recreational/social activities (2.4 per cent, compared with 0.6 per cent).

4.2 Carer's Allowance customers' access to welfare benefits and services

All survey respondents were current CA customers and had been claiming CA for a variety of lengths of time (Table 4.5). The survey data was compared with the national level data on CA customers (Table 2.2) and revealed a similar pattern. Two-thirds (66 per cent) of carers in the study had been claiming CA for over two years (compared with 67 per cent in national DWP data). Very recent claimants (those claiming for up to six months only) were the smallest groups in both sets of data (five per cent in the study and nine per cent in DWP data). Comparison of the two sets of data also showed similar patterns for male and female CA claimants, with numbers of both men and women increasing with the duration of the claim, and women representing about double the number of men in most categories, and about three times as many for those claiming CA for two years or longer (Tables 2.2 and 4.5).

Table 4.5 Carer's Allowance claimants, by gender and duration of claim

| Duration of CA claim | All | | Women | | Men | |
|---------------------------|--------|----------|--------|-------|--------|-------|
| | Number | Column % | Number | Row % | Number | Row % |
| Up to 3 months | 4 | 1 | 2 | 50 | 2 | 50 |
| 3 months up to 6 months | 16 | 4 | 11 | 69 | 5 | 31 |
| 6 months up to 1 year | 33 | 8 | 20 | 61 | 13 | 39 |
| 1 year and up to 2 years | 74 | 17 | 48 | 65 | 26 | 35 |
| 2 years and up to 5 years | 133 | 26 | 93 | 70 | 40 | 30 |
| 5 years and over | 172 | 40 | 115 | 67 | 57 | 33 |
| Total | 432 | 100 | 289 | 67 | 143 | 33 |

Source: Survey of Carer's Allowance customers, CIRCLE, University of Leeds, 2010.

The survey data also provides a picture of the other state benefits respondents were receiving (Table 4.6). The other benefits most commonly accessed were Income Support (IS) (50 per cent), Council Tax Benefit (CTB) (48 per cent), and Housing Benefit (HB) (46 per cent)¹⁹.

¹⁹ A high number of respondents (122 in combination) claimed to be in receipt of Disability Living Allowance (DLA) and Attendance Allowance (AA). Since these two benefits are the qualifying benefits for CA, it is possible that these figures are incorrect and that some respondents mistakenly ticked this part of the survey because the person they cared for was in receipt of one or both of these benefits. However, it is also possible to be a carer and receive these benefits in one's own right, as happens in some instances where couples both receive CA when caring for each other.

Older carers (aged 60+) were significantly more likely than carers in other age groups to be claiming support in the form of Motability²⁰, Blue Badge, CTB and AA. Younger carers (aged 16-34) were significantly more likely to be claiming Child Tax Credit, IS and HB.

Compared with those in the study who were only claiming CA, carers who were claiming two or more benefits (CA plus at least one other benefit) were significantly more likely to:

- be younger carers (aged 16-34) (16 per cent, compared with 7.7 per cent, $p=0.037^*$);
- have no qualifications, or to be qualified only up to GCSE level (84 per cent, compared with 16 per cent, $p=0.003^{**}$);
- be from a BAME group (76 per cent, compared with 87 per cent, $p=0.042$ per cent^{*});
- be renting their home (65 per cent, compared with 27 per cent, $P<0.001^{***}$); and
- be providing care for a child (41 per cent, compared with 23 per cent, $p=0.0012^{**}$).

Table 4.6 CA survey respondents: other benefits/support received

| Respondents receiving benefits or support | | |
|---|---------------|----------|
| Type of benefit/support | Number | % |
| Income Support | 249 | 49.7 |
| Council Tax benefit | 240 | 47.9 |
| Housing Benefit | 231 | 46.1 |
| Child Tax Credit | 151 | 30.2 |
| Disability Living Allowance | 105 | 21.0 |
| Blue Badge | 56 | 11.2 |
| Motability Help | 28 | 5.6 |
| Disability or Severe Disability element of Working Tax Credit | 24 | 4.8 |
| Attendance Allowance | 17 | 3.4 |
| Disability or Severe Disability Premium | 11 | 2.2 |
| Working Tax Credit | 10 | 2.0 |
| Direct Payment (through LA Adults' or Children's Services) | 7 | 1.4 |
| Jobseeker's Allowance | 6 | 1.2 |
| Incapacity Benefit/Employment Support Allowance | 6 | 1.2 |
| Severe Disability Allowance | 5 | 1.0 |
| Independent Living Fund | 2 | 0.4 |
| Statutory Sick Pay | 2 | 0.4 |
| Access to Work | 1 | 0.2 |

Source: Survey of Carer's Allowance customers, CIRCLE, University of Leeds, 2010.

²⁰ The Motability Scheme enables disabled people to exchange either their Higher rate Mobility component of Disability Living Allowance, or their War Pensions Mobility Supplement to obtain a new car, powered wheelchair or scooter.

Carers claiming two or more benefits were, however, significantly less likely to:

- report financial difficulties (31 per cent, compared with 42 per cent, $p=0.047^*$);
- be caring for a parent (23 per cent, compared with 37 per cent, $p=0.015^*$); and
- be:
 - providing personal care (69 per cent, compared with 85 per cent, $p=0.004^{**}$);
 - providing physical care (58 per cent, compared with 84 per cent, $p<0.001^{***}$);
 - giving medicines (73 per cent, compared with 87 per cent, $p=0.005^{**}$);
 - helping with paperwork/financial matters (68 per cent, compared with 84 per cent, $p=0.005^{**}$);
 - visiting/keeping company (77 per cent, compared with 87 per cent, $p=0.05^*$); and
 - supporting leisure activities (92 per cent, compared with 83 per cent, $p=0.029^*$).

There was no statistically significant difference between carers claiming CA only and carers who were claiming two or more benefits (CA plus at least one other benefit), by gender, number of people cared for, household size, hours of care provided, length of time caring, health or desire to work.

Almost two-thirds (62 per cent) of the survey respondents claimed three or more benefits (including CA). However, there was no significant difference by gender, age, ethnicity or health between these carers and carers claiming fewer benefits. Carers looking after a child under 20 were, however, significantly more likely than other carers to be claiming three or more benefits (80 per cent compared with 54 per cent, $p<0.001$), while carers looking after a person aged 70 or over were significantly less likely than other carers to be claiming three or more benefits (44 per cent compared with 67 per cent, $p<0.001$).

Respondents in the discussion forums and interviews tended to talk about CA without separating it from any other state benefits or care services they received; it was commonly seen as just part of a 'package' of state-provided support. Because of this, respondents frequently struggled to focus their discussion specifically on CA. Many referred to inter-relationships between state benefits, and sometimes also with support services accessed via local authorities, which they found confusing. Carers' advisers also told us that they had encountered this difficulty, several noting that the relationship between CA, Carer Premium and Direct Payments was particularly complex and difficult for carers to understand.

The discussion forums and interviews confirmed previous research findings about the availability of formal support services, including that there was considerable geographical variation (Buckner *et al.*, 2010; CSCI, 2009). In this study, carers based in areas which had well developed carers' networks (e.g. an active carers' centre, relevant voluntary organisations, and/or healthcare professionals/GPs responsive to carer issues), were noticeably more aware of existing services than those who lived in other areas. Awareness of services and support varied among carers, particularly about what was available via social services: older carers were more likely than younger ones to be familiar with this kind of support, as were those caring for someone with a condition involving regular contact with health or social care networks and professionals (through which information on carer support and services had been obtained). Carers caring for a person with an allocated social worker or who had had direct contact with care organisations (e.g. a voluntary group concerned with the condition of the person they cared for) were more likely to have received advice about formal services, as were those carers who had been contacted by social services during a hospital discharge procedure involving the person they cared for. Isolated carers, including some single parents looking after a sick or disabled child, seemed to be the least likely to know what might be available to them. This

was compounded in some cases by their ambivalence about receiving support with their caring role; some were less likely to seek information in consequence.

Few respondents in the study had had their needs explored in a formal Carer's Assessment²¹. Many were not even sure what this was. However, several carers thought they might have had their needs assessed when they first came into contact with social services (without the procedure being identified as such). Others were not sure, but wondered if a Carer's Assessment might have been conducted at the onset of care – a stressful period in their caring responsibilities – and felt they might have forgotten about it.

Some carers reported that there can often be a key moment in the history or development of a care situation when they become aware of available services and support. Box 4.1 illustrates the kind of formal care services accessed which can help a carer in receipt of CA to negotiate their caring situation.

Forum respondents and interviewees expressed considerable dissatisfaction with the quality of formal care services they had encountered. Several spoke about inadequate services, with caring needs left unmet or carers expected to pay for essential costs involved in caring for a disabled person which they could not afford (e.g. essential home improvements). Some felt resentful as they believed paid care workers provided a less comprehensive, often poorer quality, care than they themselves provided every day. Some emphasised the difference between CA and the higher sum of money a paid care worker receives for carrying out identical or very similar tasks. Others pointed out that home care workers often have a less intensive workload, with fixed hours of employment allowing them to leave the care situation behind at the end of each day.

'The only difference between us and the carer professional [is] we've not got the certificate to say that we're professionals, and if we did we'd be paid by the hour.'

(Female carer, forum: complex benefits)

Box 4.1 A CA customer's caring situation: the role of formal services

Frank has been caring for his wife for 20 years, since her initial diagnosis with Multiple Sclerosis. His demanding caring role forced Frank to give up paid work eight years ago and he is now nearing retirement age. Frank has been getting CA since he gave up paid work, although it is only more recently that he became aware of other support services he could access. Frank's wife is now attended by professional care workers twice a day to help her get up and go to bed. Frank only began to access this support through social services after his wife experienced a period in hospital. He was made aware of the services available by hospital staff. Frank believes that it took a crisis in his care situation – his wife's hospital stay – for him to become aware of, and to apply for, services he feels ought to function alongside CA as a 'package' to help him care for his wife. He is now reasonably happy with the support he receives, although he claims it took a long time to establish this.

(Male carer; forum: LLTC)

²¹ Carer's Assessments were introduced in the Carers (Recognition and Services) Act 1995 and carers' rights in relation to these are also a focus of subsequent legislation, the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004. Carers providing a 'regular and substantial amount' of care are entitled to a separate carer's assessment of their needs and views by their local social services department (see Clements [2009] for detailed discussion).

Carers commented that they provided multiple forms of care which would otherwise require a range of different professional care or health workers.

There was a general consensus that support services were difficult for carers to access, and that information about what was available was not readily volunteered by social services representatives.

'It's like you have to be in some kind of secret club to know your way round the system [...] I'm sure there must be certain things that, you know, there's bits going on and, me personally, I don't know anything about them; I wouldn't know who to phone to find out, because the social worker didn't say much, you know, the person who came round, what's it called, the occupational therapist, she didn't open her mouth.'

(Female interviewee; caring for a parent)

Most carers felt that they had been forced to invest a lot of time and effort in applying for services, often describing the process as a 'fight' or a 'battle'. They had found this onerous and very demanding alongside the everyday stresses of their caring role.

'The thing that really annoys me the most is that these services are out there. They're there somewhere, but they make them so hard to get to that, like I said, I don't have the energy to fight for these things.'

(Female carer; forum: complex benefits)

Other carers said it had taken years to build up a 'package' of appropriate services. Although these services were sometimes described as appropriate to the care situation, there was nonetheless a good deal of bitterness about the fact that it had taken so long to get them in place.

While some carers in the study were satisfied with the services they received, there was a common feeling among them that the services they had eventually managed to access were not adequate to support them fully. Older carers often expressed dismay about the few services they had managed to secure, claiming to be in only a slightly more advantageous position than they had been years earlier.

'Yeah, and the fact that everything I try to do and everything that, you know, any help I try to get, or everything we try to look into – it's just a brick wall all the time. So you get one nice social worker comes in, [who says], "Oh yes, we'll do this, this and this." And then another year down the line, nothing's happened, and it's not just weeks that are going by, it's years that are going by.'

(Female interviewee, caring for an adult child)

Some carers in the study were accessing care services which they had to pay for (e.g. childcare services for an autistic child). Deciding to seek private services generally happened because the carer had previously experienced a lot of difficulty in accessing support from a local authority or wished to avoid the complications they had come to believe were always involved. These included out-of-date information, overly intrusive or complex assessment procedures, or a shortfall of places on schemes designed for the cared for person's needs.

In the forums and interviews, carers said that what they most wanted was a break from caring.

'A break's one thing [...] My [local authority] used to give me a massage and that was very good because it did make you... It was like an hour to yourself, which sometimes I don't feel like I actually have.'

(Female interviewee, caring for a parent)

Other respondents claimed that taking a break would only be possible if suitable alternative care was provided. Some carers thought a sitting service would be particularly useful, with appropriately trained staff taking charge while they enjoyed a break. This was especially true of carers of a sick or disabled child, while carers of older people tended to think that day care services would be more appropriate to their needs for respite/breaks.

Among other services carers in the study wanted were:

- specialised equipment, specifically geared towards the condition of the cared for person, to help them with the care they gave;
- help with the transportation costs of the cared for person (attending hospital appointments was a particular problem);
- schemes like Direct Payments, as long as these avoided complex administrative processes (some carers claimed that handling a budget would only add to their everyday caring burdens);²²
- short courses providing carers with an 'outside interest' (one respondent enjoyed attending a weekly arts class) with alternative care arrangements to allow this; and
- carer support groups at which advice was offered, allowing ideas and experiences to be exchanged with other carers.

Most forum and interview respondents also relied on their own informal networks of support. These included asking friends and/or relatives to help with their caring duties – either by directly looking after the cared for person, or by helping in other ways, such as carrying out shopping, offering emotional support to the carer, or even providing financial assistance. Box 4.2 illustrates how such informal arrangements can work in a common caring situation.

Box 4.2 Informal help in a CA customer's caring situation

Judith once worked full-time, but became ill and applied for state benefits after leaving her employment. Since that time her sister had suffered a major spinal injury and Judith was now the only person available to be her carer. Judith also now cares for her elderly parents, claiming both CA and IS. Judith cannot find suitable employment because of her caring duties and her own existing health problems. The only way she can cope with her lack of money is by relying on her adult children, both in full-time employment, to give her money for petrol and other everyday necessities. Friends occasionally help out with the care Judith provides for her elderly parents. Without this informal help, Judith believes she would not be able to continue providing adequate care for her sister and parents. She also thinks it is unfair that although she is caring for three people, she is allowed to claim CA only once.

(Female carer; forum: older person)

Although informal care arrangements and the support of other family members were crucial to many respondents, some noted, sometimes with a degree of dismay, the lack of help they received from family and/or friends. Sometimes this was because the cared for person required specialised care, such as injections; some carers felt other people would not want this responsibility (and some did not feel comfortable offering such responsibilities to others). A few felt they had been effectively abandoned in their care situation by other family members. These were often those caring for a parent without help from siblings, or, as below, for an adult child.

²² The development of personalised budgets is also relevant. For an evaluation of these, during their introduction as pilot schemes, see Glendinning *et al.*, 2008.

'... I find that I've lost the family support, because they're not children any more. He's an adult, he's 25 and I've lost that circle of support, my brothers, my sisters have had enough [...] My parents are in their eighties, my father's 88, my mother's 84, they can't look after him now. So I've lost that circle, as he gets older, I've lost the circle. So I'm on my own.'

(Female carer; forum: seeking work)

Some carers in this position said they resented the fact that other family members had a life of their own while they were restricted by the care situation. Respondents also expressed resentment about the fact that, once they had agreed to care for one relative, it was more likely they would be expected to look after another relative who developed a need for care.

'I've older brothers and sisters, and now my parents are in their eighties I'm expected, because I'm looking after my son, that I'm not the working one, to look after my parents. I get no recognition, but they expect me to do it. My family expect me to do that.'

(Female carer; forum: seeking work)

This issue is particularly relevant to understanding CA, as some carers believed it was unfair that, when caring for more than one person, they could claim CA only once. Some in this position had found themselves with multiple care responsibilities and neither the informal help nor adequate financial support to cope effectively.

Some CA customers in the study sought access to dedicated local Carers Centres, or to voluntary organisations dedicated to the condition of the person they cared for. These organisations commonly arrange 'fun' day events for carers and their cared for person, as well as relaxation sessions for carers (e.g. aromatherapy and massage); they hold drop-in sessions to offer advice, and coffee mornings to enable carers to meet others in similar situations; they provide telephone helplines, signposting to formal services, and a wide range of supportive literature available from their offices or online. Carers in one of the study's forums spoke very highly of the local Carers Centre which was considered invaluable as a source of advice and support; carers spoke particularly highly of the understanding which staff at this organisation could offer – this was felt by respondents to be something they did not often get from social services and/or other government agencies and departments.

4.3 Claiming Carer's Allowance

4.3.1 The decision to apply for Carer's Allowance

There was some variation in carers' experiences of starting to claim CA. While for some there had been a 'tipping point' in their caring situation, with a clear and identifiable moment at which circumstances changed, for others the decision to apply for CA had been in response to more gradual changes. For most, increased caring responsibilities, especially if these affected the carer's capacity to seek or maintain paid employment, were involved:

'This is just over a year now that I've finished my work. This year, last February or whatever, during my week's holiday, I began to notice it more – because I was in the house every day – that [my wife] wasn't sort of coping with it on her own. [...] I felt that help was needed 24 hours a day, and we discussed it, and decided that the best arrangement was me giving up my work, was caring full-time now.'

(Male interviewee, caring for a spouse)

A new awareness that CA was available as a benefit relevant to their situation was also frequently mentioned. Several respondents had been caring for a long time before becoming aware of CA, and

it was only after they had heard from specific sources (see below) about the existence of CA that they had applied for it. A few carers reported that they had previously been receiving Jobseeker's Allowance (JSA), and on being advised that they qualified for CA, had decided to apply as their now more demanding caring seemed to justify taking this step.

Some explained that deciding to claim CA was, in part, an attempt to avoid the 'stress and hassle' (female carer; forum: working) involved in claiming JSA. Others said they had decided to apply for CA after overcoming more general initial reluctance to seek state benefits (feeling there was a stigma attached to doing so).

For most, applying for CA had not been experienced as a choice. As one respondent put it, CA was the 'only option' in their caring circumstances. The unpredictability of the cared for person's condition almost always complicated the carers' employment options, and a lack of other assistance with the care needed (whether formal or informal support) hampered them in making other arrangements. Unable to work in the way they would prefer, and having few other resources, many respondents had felt constrained in their choices, both to become a carer and to claim CA. Most could see no alternative: a sense of obligation propelled them into becoming a carer, while financial necessity forced them to apply for CA.

Carer: 'It was because I was put in a situation where I couldn't work full-time and knew that getting Carer's Allowance was an option. And I did ring and check, you know, it would be available, and they said yes. So I just had to do it. It wasn't really a choice.'

Interviewer: 'So there were no alternatives?'

Carer: 'No.'

(Female interviewee, caring for an adult child)

4.3.2 Attitudes to claiming state benefits

Some respondents said they were unhappy about having to access state benefits and that, if they were able to survive financially, they would rather carry out their caring roles without doing so. For some, the stigma attached to claiming benefits was keenly felt (see Box 4.3).

Some respondents' initial reluctance to apply for CA arose from their perception that claiming state benefits made seeking employment extremely difficult (an issue also explored in Chapter 6). Others had been reluctant to apply, as they felt claiming state benefits was always complex and difficult, carried a risk of being unsuccessful, and was likely to involve negotiating stressful application procedures and making appeals. As a result, they had initially felt it would be easier to try to cope with the caring situation without state support; only when care demands escalated did this perception change.

Box 4.3 Carer's Allowance and the 'stigma' of state benefits

Alison was already caring for her husband when she became pregnant. Members of her maternity group persuaded her that she would need some help in her caring role once her child was born. Alison had initially felt reluctant about accessing state support because of the stigma she believed was attached to doing so. However, as her everyday life, including the care she gave, grew increasingly complicated and demanding, her 'pride was chucked out of the window', and she found herself with no choice but to seek state help. She has yet to tell even her closest friends that she receives CA because she still feels there is a stigma attached to receiving state benefits.

(Female carer; forum: new to CA)

Several respondents (particularly younger carers who were new to caring) felt what they called 'guilt' about receiving CA, especially when looking after relatives who were their child or their parent. Deep down, they felt the care they provided was an aspect of their parental or other family responsibility, and anxious about how others with ordinary parental responsibilities would perceive their claiming support or benefits. As one carer put it:

'When it's your child, there's that responsibility there, because it's your child. And then there's the guilt about taking the money for looking after your own child, and then trying to differentiate whether you are doing extra than everybody else, even though you know you are [...]. And then you feel the resentment, and then you feel guilty. So then it's mixed emotions – but when it's your child, you feel more responsibility.'

(Female carer; forum: complex benefits)

Those who expressed views of this type also felt they were looked down upon by other members of society for receiving state benefits for the care they provided. For some, this contributed to mounting anxiety and unhappiness in their lives. A belief that some other groups were treated better than carers, expressed bitterly by a number of forum respondents and several interviewees, was also summed up by one carer.

'They bring everything in stages, and we're always at the end [...] You're way at the end, because it comes into deprived areas, and then it comes into something else, and something else, and [our needs are] way at the end of everything, way at the end.'

(Female carer; forum: seeking work)

4.3.3 Sources of information and advice about claiming Carer's Allowance

When considering making an application for CA, respondents had relied on numerous sources of information. Those most commonly mentioned were other carers, carers' networks or organisations, family members (who had often conducted Internet searches on their behalf), health workers, social workers, GPs, and other contacts they had made during hospital discharge procedures.

The carer advisers contributing to this study gave a detailed list of the sources of information they thought regularly drawn upon by carers when first applying for CA. This was based on their direct experience with new applicants (see Table 4.7).

Table 4.7 Sources of information about Carer's Allowance for claimants: advisers' perspectives

| National/government organisations | Charity/voluntary organisations | Other sources |
|--|--|---|
| <ul style="list-style-type: none"> CAU Carers Direct Jobcentre Plus Directgov.org NHS Choices line Local authority benefit advice teams Medical staff, including GPs and nurses Social workers | <ul style="list-style-type: none"> Carers UK Princess Royal Trust for Carers Crossroads Care Age Concern Macmillan Advice charities – e.g. MIND Alzheimer's Society Citizens Advice Bureau Welfare Rights information service Benefit lines other than CAU | <ul style="list-style-type: none"> Word of mouth from other carers Internet searches. Friends or relatives Solicitors/accountants Magazines Yellow Pages Carers Rights Day, Carers Week, Carers UK AGM, (etc) events |

In general, carers in the forums and the interviews felt the information they had received about CA had been accurate; very few reported receiving poor advice from any particular source. Some felt appropriate information had not been readily available to them at the onset of caring, however, and that official sources do not advertise CA widely enough, leaving carers dependent on informal sources:

'I was different, because I was getting Income Support, because I had my young boy and wasn't working. And it was only when someone actually stopped me in the supermarket, when he was playing up once, and (...) she said, 'Oh, you know you should be getting Carer's Allowance.' I said, 'He's my son, I've got to care for him.' She said, 'No, until he's diagnosed' – because I had been waiting till he was diagnosed – 'from the moment you get referred, you can get Carer's Allowance if he needs it.' (...) It was only a complete stranger, stopping me in the supermarket. No-one told me that.'

(Female carer; forum: LLTC)

The perceived lack of publicity on CA could sometimes exclude carers who had no contact with formal services. Some carers, caring for someone without a physical condition (e.g. suffering from learning difficulties), expressed the view that, although they had heard of CA, they had assumed it was unavailable to them and had, therefore, never enquired about it:

'In the past I would've thought [CA] was for caring for someone who is ill, physically ill. It's not something that one is likely to look into unless you're in [what you understand to be] a caring situation. Unless you've got a disabled person you are caring for, you don't really look into that sort of thing.'

(Female interviewee: carer of an adult child)

Other carers felt that formal agencies had an inadequate understanding of the complex circumstances of their lives and how these related to CA; this could sometimes result in carers who were eligible to claim CA not doing so:

'Well, it's something that I didn't realise I was entitled to until a few years ago. I was actually misinformed about the Carer's Allowance. I assumed I wasn't entitled to it. Yes, it was the people at the Jobcentre. [...] When I was actually in employment – because I receive an army pension, I'm an army widow – they told me that I wouldn't be entitled to Carer's Allowance, but it turns out that I subsequently was told different. So I applied and I was told that I was [eligible], that the army pension didn't come into it. Well, I don't know [how many years of CA I missed] – you see, I was working. I know there's an earnings threshold on Carer's Allowance, so I probably missed out on a couple of years, something like that.'

(Female interviewee: carer of an adult child)

Carer advisers interviewed in this study felt sources of information about CA varied in quality. Some felt that organisations which do not focus specifically on carers (citing for example, Jobcentre Plus and NHS medical staff) sometimes supplied incorrect information. DWP call centres (although not the Carer's Allowance Unit (CAU)) were mentioned by some as providing information of variable quality, although advisers at the CAU pointed out that a great deal of effort had been made in recent years, by the various benefit units, to develop shared knowledge across different DWP departments. The CAU was well regarded as a source of information by many carer advisors, and staff at the CAU presented a range of evidence supporting their conviction that the CAU provided good quality, reliable information.

All carer advisers interviewed shared a view that incorrect information could have very unfortunate consequences for carers, sometimes resulting in their having to reapply for CA, significantly lengthening the time before CA was awarded, and stressed the importance of speedy and accurate responses to carer enquiries.

4.3.4 Applying for Carer's Allowance

In reflecting on the process of applying for CA, respondents often struggled to separate CA from other state benefits they received. Consequently, some of their frustration about complex application forms may not have been specifically about CA. The forms for DLA, for example, which carers often filled out on behalf of those they cared for, were sometimes the main focus of their criticisms. Some said applying for CA had been relatively straightforward, compared with claiming other benefits. Staff at the CAU pointed to evidence that their customers were more satisfied than those who used other benefit lines, a point with which other carer advisor respondents agreed.

There was nonetheless some frustration among carers arising from their lack of understanding of how best to present the information to demonstrate they qualified for CA. Several forum participants had been denied CA following their initial application and had needed to reapply. Even when their second application had been successful, the overall process had increased their feelings of frustration about dealing with benefit agencies²³.

Carer advisors also commented on a few other issues. One felt the impersonal nature of the state benefits application system (via telephone and post) was alienating for some claimants, particularly those who were older. Another noted that, as CA is linked to the benefits received by the person cared for, problems arise if that person refuses to access the benefits they are entitled to, leaving the carer in the very frustrating position of being unable to apply for CA.

Carer advisors also claimed that the rules and eligibility criteria for CA sometimes cause problems when a caring situation is complex, for example if more than one individual is providing care for a severely disabled person. In such circumstances, it can be difficult to decide who the claimant should be, especially as caring often involves a whole family. The reality of a caring situation is not always simple, with one cared for person being looked after by one carer, yet the CA system is not responsive to this complexity.

Among carer forum respondents and interviewees, the complexity of CA rules was noted as a significant barrier, especially for older carers or for non-native speakers of English. Staff at the CAU forum noted that applicants who cannot speak English well sometimes recruit their children as impromptu translators, and that much frustration and distress can arise from this. CAU staff highlighted the CAU language service which can provide support during CA claims, although phone line translators were said to be of variable quality, and some translators were said to have a poor understanding of CA rules²⁴.

4.3.5 Assessment of Carer's Allowance applications

Some forum respondents and interviewees drew attention to the attitudes of staff working in the state benefits system. They felt there was generally a sceptical attitude towards claimants, and that the questions asked, and the application forms used, were designed to 'catch people out'. It was difficult specifically to distinguish their comments about CA, as many claimed a range of benefits.

²³ None of the forum respondents had been through the CAU appeals process.

²⁴ This ought not to affect carers enquiring about CA, as the translator would normally be talking via a member of CAU staff trained on CA eligibility rules.

Some respondents found the overall benefit assessment process extremely intrusive, mentioning that it occasionally involved professionals conducting house visits. Some felt these could be poor at capturing understanding of the caring situation, as the person cared for could simply be having 'a good day' (male carer; forum: older person). They noted also that the CA assessment process involved benefit agencies having access to their bank details and making many personal enquiries, a process some felt compromised their dignity.

'From being quite a private person and quite a solitary person, to all of a sudden to have everything in your life, everything, there's nothing sacred, it just, it threw me, I just couldn't deal with it...'

(Female carer; forum: working)

Some felt they were distrusted during the application process, as they repeatedly had to report their current income. The general feeling was of a system focused on preventing any possibility of benefit fraud, rather than on assisting them in making their claims in a way which was sensitive to their everyday difficulties.

A few claimed that the rules affecting CA could be applied in an arbitrary and inflexible manner. Some said they, or others they knew, had 'lost' their CA if they earned as little as 'a few pence' (female carer; forum: seeking work) over the official earnings limit. One carer had once informed the CAU she had unwittingly earned more than the weekly earnings limit, and had been offended by the way she was treated by a CAU staff member.

While it was impossible in the study to verify these claims, they did present a rather different picture from that given by CAU staff, who explained that they tried to achieve the best outcome for the customer within the eligibility criteria. One advisor explained that, in cases of 'employment where the earnings are within £20 of the earnings limit' (CAU staff member), carer expenditure (such as trade union fees, etc) could be taken into consideration and deducted from the total amount of money a CA recipient had earned.

'Generally, we try and do what's advantageous to the customer. If it would be advantageous to the customer to average the earnings then we would consider averaging it. But if you say, well, for six months of the year they weren't working but for the other six months of the year they earned £50,000, we would only look at the six months that were under and look to see whether or not we could award them. If they were under our limits that six months, but then it's a discretion decision.'

(CAU staff member)

Another said there was flexibility in how CAU staff calculated the hours of care:

'...if they have 35 hours caring or longer: say, for example, they're there Sunday, the whole day Sunday is 24 hours and then 11 hours Monday, we would class that as 35 hours. It doesn't have to be split evenly throughout the week. We just take it as read that if they say that they were there morning and night and morning on one day that would be 36 hours.'

(CAU staff member)

None of the forum respondents or interviewees, however, had personal experience of this kind of flexibility, and some were convinced that such flexibility is never encountered by carers. One respondent at the CAU observed, ultimately assessors 'can't knowingly risk the customer having an overpayment to their benefit because of our decision-making process.' (CAU1)

Those who did speak explicitly about the CAU noted that it was the easiest of the various state benefit agencies to deal with.

A few respondents commented critically on the fact that, when an application was made, only three months of back-dated CA is payable, even if the applicant has been caring, meeting qualifying requirements for CA, for a much longer period.

'...obviously I'd been caring for her [sister] a lot longer, but I got three months [...] They had all the medical information there. They could see from the time she'd collapsed and had the operation, [...] they could see, from that moment in time [several years earlier], she needed help.'

(Female carer; forum: new to CA)

These respondents felt this rule was particularly unfair, as (if benefit agencies find that payments have been made to claimants in error) all money owed by the carer is recoverable, sometimes over a considerably longer period than three months. Some carers in the study had found themselves owing their local authority considerable sums as a result of previous overpayments, and these respondents were particularly critical of the three month limit on CA back-payments.

4.4 Carer's Allowance: interaction with carers' financial circumstances

4.4.1 Income Support and Carer's Allowance

A difficulty with CA regularly cited by forum respondents and interviewees was the problematic way in which it interacts with IS. Two broad issues were highlighted: first, that for IS purposes, CA counts as income, and is deducted from IS entitlements, with CA effectively subsumed into IS. Carers who are IS claimants can receive an additional payment (Carer Premium, at the time of writing, £30.05). From their perspective, this creates a shortfall in what a carer would get if CA was additional to IS, as some felt it should be. The amount of IS to which a claimant is entitled varies according to their circumstances and financial situation, meaning the final amount received also varies, leaving some carers confused.

Second, while a person claiming CA may earn up to £100 per week, the earnings limit for IS is £20. Thus, carers on IS find that any income they earn over £20 per week is deducted from the IS they are awarded. This factor was cited as an additional problem for carers wanting to combine work and care, and also contributed to their perception of being 'trapped' on benefits.

4.4.2 Other benefits and Carer's Allowance

Some carers had been in receipt of JSA prior to making their claim for CA. These respondents felt there was noticeably less 'hassle' involved in receiving CA than JSA, pointing out that benefit agency staff (whom they felt lacked an adequate understanding of carers' needs and responsibilities) tended to pressurise carers who were JSA claimants into returning to work when this may not be appropriate.

Carer: 'You've still got to go to the Jobcentre every six months and explain why you can't work [...] I find them, depending on who you get, very pushy: 'Why can't you work? Oh I understand that, but he goes to school every day, so why can't you work part-time hours while he's at school?' Things like that. They don't understand, and it's very, very pushy.'

(Male carer; forum: complex benefits)

Others, however, described experiences with helpful advisers who, on reviewing their caring circumstances, had recommended that they claim CA. These carers noted that the different rules for CA were positive for carers, and involved less stress and pressure in their lives.

As shown above, carers often receive numerous other state benefits, and the way these interact is often extremely complex. Respondents regularly found these processes confusing and difficult to articulate; some felt the professionals who advise them (e.g. Jobcentre Plus staff and health care workers) also struggled with these multiple and complex rules. Respondents claimed this complexity made it difficult for them to assert their rights, while also increasing their vulnerability to (what they perceived to be) inappropriate treatment from the benefit agencies.

Only one of CA, JSA and State Pension can be received at any one time, even when there is entitlement to several. This policy rationale was not understood by most carers in the study. None appeared to have an awareness of the 'underlying entitlement' and 'overlapping benefit' concepts. Carers' advisers noted, however, that documentation informing carers about these aspects of the system causes considerable confusion²⁵. They highlighted the fact that CA entitlement letters sent to carers affected by these rules states both that they are eligible for CA and that they will not in fact receive it, causing, in their experience, significant distress to carers.

Carer advisers also pointed out the impact CA has on the benefits package available to the person cared for. If a carer successfully claims CA, this limits the Premium options available to the person they care for. Furthermore, the rules for calculating both Disability Premium and Direct Payments take carers' income into account. One advisor indicated that how CA impacts on the cared for person's benefits package – an important issue in the emerging context of individual budgets, direct payments and personalised support packages for sick and disabled people – had not yet been fully assessed.

²⁵ DWP introduced a new letter (from October 2010) designed to avoid this kind of confusion on the part of CA customers.

5 Carer's Allowance customers' experiences of caring

In this chapter, Carer's Allowance (CA) customers' experiences of providing care, including the intensity and duration of their caring roles, the financial circumstances with which they are coping, the type of care they provide, and characteristics of the person they care for are considered. The chapter also examines evidence about how carers spend CA, and its importance for them as a source of income.

5.1 Carer's Allowance customers' caring situations

Among the CA recipients included in the survey, many had been caring for a considerable time (approximately 40 per cent for five years or more); well over half were caring very intensively (50+ hours per week). Almost 40 per cent were in difficult financial circumstances, with a similar proportion 'just about getting by'. The picture relating to these aspects is presented in Table 5.1.

Table 5.1 Caring circumstances of survey respondents

| | % | Number |
|--|------|--------|
| Duration of caring role (n=446) | | |
| Up to 6 months | 4.7 | 21 |
| 6 months up to 1 year | 7.8 | 35 |
| 1 year up to 2 years | 17.5 | 78 |
| 2 years up to 5 years | 29.8 | 133 |
| 5 years up to 10 years | 22.9 | 102 |
| 10 years or over | 17.3 | 77 |
| Weekly hours of care provided (n=446) | | |
| Less than 25 hours | 14.4 | 64 |
| 25-34 hours | 2.0 | 9 |
| 35-49 hours | 17.5 | 78 |
| 50-74 hours | 12.3 | 55 |
| 75-99 hours | 7.8 | 35 |
| 100+ hours | 46.0 | 205 |
| Financial situation (n=498) | | |
| Living comfortably | 3.4 | 17 |
| Doing all right | 17.1 | 85 |
| Just about getting by | 39.2 | 195 |
| Finding it quite difficult | 19.5 | 97 |
| Finding it very difficult | 19.5 | 97 |
| Don't know | 1.4 | 7 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

Note: percentages are for respondents who answered relevant questions; see Appendix B4 for precise wording.

Most (70 per cent) respondents had been caring for two years or longer, among them 40 per cent who had been caring for more than five years. Thus, newer carers (those caring for up to two years) constituted less than a third (30 per cent) of the sample (see Table 4.3). This pattern in our sample is very similar to that seen in Department for Work and Pensions (DWP) statistics for all CA customers at national level (shown in Chapter 2).

Although nearly a quarter of carers in the study had received CA from the start of their caring role (23 per cent), most (77 per cent) had been caring for some time before they started to receive this benefit. Well over half the survey respondents (54 per cent) said they had been caring for at least two years (and 28 per cent for five years or more) before they started to receive CA (see Table 5.2).²⁶

Table 5.2 Length of time caring before receiving Carer's Allowance

| Duration of caring role | Number | % |
|--|------------|------------|
| Less than 1 month (receiving CA from start of caring role) | 97 | 23 |
| 1-5 months | 27 | 6 |
| 6-11 months | 27 | 6 |
| 12-23 months | 45 | 11 |
| 24-59 | 110 | 26 |
| 60+ months | 118 | 28 |
| Total | 424 | 100 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

Analysis of the survey data included comparison of the responses of shorter term carers (less than five years) and longer term carers (five years or more). Longer term carers in the study (with results of the tests for statistical significance indicated) were more likely (than those with fewer years of care) to be:

- women (73 per cent, compared with 61 per cent, $p=0.008^{**}$);
- aged 35-59 (77 per cent, compared with 62 per cent);
- caring for a child under 20 (35 per cent, compared with 18 per cent, $p<0.001^{***}$);
- caring for an adult child aged 20+ (12 per cent, compared with 0.6 per cent, $p<0.001^{***}$);
- in poor health (30 per cent, compared with 20 per cent, $p=0.018^{*}$);
- caring for 100+ hours per week (52 per cent, compared with 36 per cent, $p=0.001^{**}$);
- multiple benefit claimants (66 per cent claimed CA and at least two additional benefits, compared with 54 per cent of other carers, $p=0.007^{**}$);
- living in the same household as the person they care for (93 per cent, compared with 77 per cent, $p<0.001^{***}$); and
- living in larger households (3+ people) (35 per cent, compared with 35 per cent, $p=0.049^{*}$).

These longer term carers were also less likely than other carers to be:

- aged 16-34 (11 per cent, compared with 23 per cent, $p=0.001^{**}$); and
- caring for an older person aged 70+ (20 per cent, compared with 33 per cent, $p=0.001^{**}$).

²⁶ Some carers may have included a previous claim for CA's predecessor benefit, ICA (Invalid Care Allowance).

There was no statistically significant difference between long-term carers and other carers in relation to employment status, financial situation, desire to work, or whether they had given up work and why, or in the number of people they cared for.

Among carers who participated in the forums and the interviews, those who were long-term carers were observed by the researchers to be perceptibly more:

- resigned to, but also more likely to feel bitter about some aspects of being a carer;
- likely to be sceptical about the provision and efficacy of formal care services; and
- likely to feel trapped by their caring role.

Long-term carers were also more likely to have resigned themselves to setting aside personal aspirations, at least until their care situations had come to an end. This observation may arise from their longer experience of caring but could also reflect poorer support for carers in the past, or other factors. One carer explained:

'I haven't got any [aspirations], I'm not allowed to have any at the moment, because I daren't. I mean I have all the goals in life that I haven't actually achieved, because I've been here looking after [son] for 33 years. There's quite a lot of them backed up, you know! But until I get him sorted out, there's no point me even thinking about it.'

(Female interviewee, caring for an adult child)

Carers who were newer to caring, particularly the younger carers involved in the forums, were more likely to express plans for the future in the form of career aspirations and having 'a life of their own' once the care they provided had ended or become more manageable. This applied even for those caring for someone to whom they had a lifelong commitment, such as a sick or disabled child. In these cases, carers hoped support services, including schools, would in the future allow them to pursue new pathways, either in education or in paid employment.

The study also explored the extent to which respondents were caring very intensively. Over 45 per cent reported caring for over 100 hours per week, with a further 38 per cent caring for between 35 and 99 hours per week. Some (16 per cent) stated that they were caring for fewer than 35 hours per week²⁷. Many respondents provided regular care for much more than 35 hours each week, some noting that their caring role never truly 'ends' (see Table 4.3).

'When you think that most people clock off work at 5 o'clock, people like us who are 24 hour carers, we carry on.'

(Female carer; forum: LLTC)

Carers with particularly demanding caring roles were also well represented in the forums and the interviews. They commonly described their care as physically and mentally exhausting, often involving periods of crisis during which they sometimes felt they could no longer cope. These carers were 'on duty' all day, often also with caring duties necessitating their intervention at night. As well as providing practical and physical help, they frequently accompanied those they cared for to hospital appointments and liaised with other health services on their behalf. (Figure 5.1 summarises

²⁷ To qualify for CA a person must be caring for 35 hours or more per week. Of those who claimed to be caring for fewer than 35 hours per week (73/446), some may have misunderstood the survey question, giving the number of hours they cared for each day. Alternatively, they may have either (i) calculated their hours of care using different criteria from those they used when making their CA claim, or (ii) had different caring circumstances, when surveyed, from those they reported when making their claim.

the type of care they provided.) Many described their lives as dominated by the care they provide, to the degree that they had no 'life of their own', and some felt there was no-one to turn to for help and support.

One carer reflected on her feelings, sometimes of desperation, pointing out that help from someone who could negotiate available support systems on their behalf could really help:

'Every so often I used to [...] get upset and go to my doctor and say, 'You have to help me.' One doctor wasn't helpful at all, because he kept [saying], 'You know she's [my mother] old'; another doctor was extremely helpful to me, thank God, and I did try to sort things out, which it did. I got the stair lift and got a bit...and it's only because she sort of actually realised that I did need the help, so she was brilliant. Because I wouldn't have known my way around the social services, to actually get (...) I probably could get more stuff; I fought for years to get central heating and luckily I ended up phoning up our MP and crying my eyes out, and she got us central heating last April, which is just as well, because my mum's bedroom was -7° you know.'

(Female interviewee, caring for a parent)

As indicated in Chapter 4, the forums included many carers who felt it had been extremely difficult to get any kind of support, including that needed to prevent crises in the care situation arising.

Most in the forums and the interviews explained that the onset of care had involved significant changes to their lives. Loss of (or a reduction in) paid employment was a major impact for some, and many carers had struggled to adjust to being at home more regularly, with feelings of social isolation and a lack of confidence and/or self-esteem commonly expressed.

'To be perfectly honest, my confidence, my sense of self-esteem, everything was just below zero, it was shocking. You know, from being a businesswoman to being a carer, it was like, what's happened? It was...it was awful.'

(Female carer; forum: working)

In the discussions, carers of sick or disabled children and those who cared for someone who had suffered a sudden onset condition often said they had found it particularly hard to adjust, largely because the care situation had been unanticipated. Carers of people whose condition had been expected (e.g. frailty in an elderly parent) had also often found their lives became dominated by constant, demanding and repetitive patterns of care. Among the major adjustments carers mentioned were:

- family life compromised (some felt they were neglecting other members of their family, especially children, giving rise to feelings of extreme guilt);
- extra financial pressure on other household members (e.g. on a husband whose wife had been forced to give up her job to care for her mother);
- difficult pressures on new partners (for parents caring for a disabled child, complicating their relationship);
- lifetime savings dwindled by the costs of care;
- adaptations to the carer's home to accommodate the cared for person (e.g. specialised equipment to enable frail people to go up and downstairs);
- limitations on social and recreational lives, with carers having little time for themselves; and
- abandoning long-term aspirations/plans for job, career, education, or retirement.

When faced with care, many respondents in the forums and interviews said they had tried to cope by holding on to a few small moments of personal satisfaction. As one put it:

'It's little things, it's not massive things, it's little things that you can't do without having to have a big plan in place, you know, to do it. I can't imagine just being able to say, 'Do you want to go and stay at so and so's?' Like my sister lives in [...] 'Do you want to come down for a few days?' Except it'll take me two weeks to sort it out at the moment, whereas if I didn't have that I could just go, 'Yeah, all right then, I'll come.' It's little things, it's not massive things.'

(Female interviewee, caring for an adult child)

By far the most commonly expressed way carers coped with the demands of their caring roles was through paid employment. As discussed in Chapter 6, paid work offers carers financial, social and other benefits which many find very useful. Even those who were not in paid employment tended to view a paid job as crucial to a carer's well-being and capacity to cope.

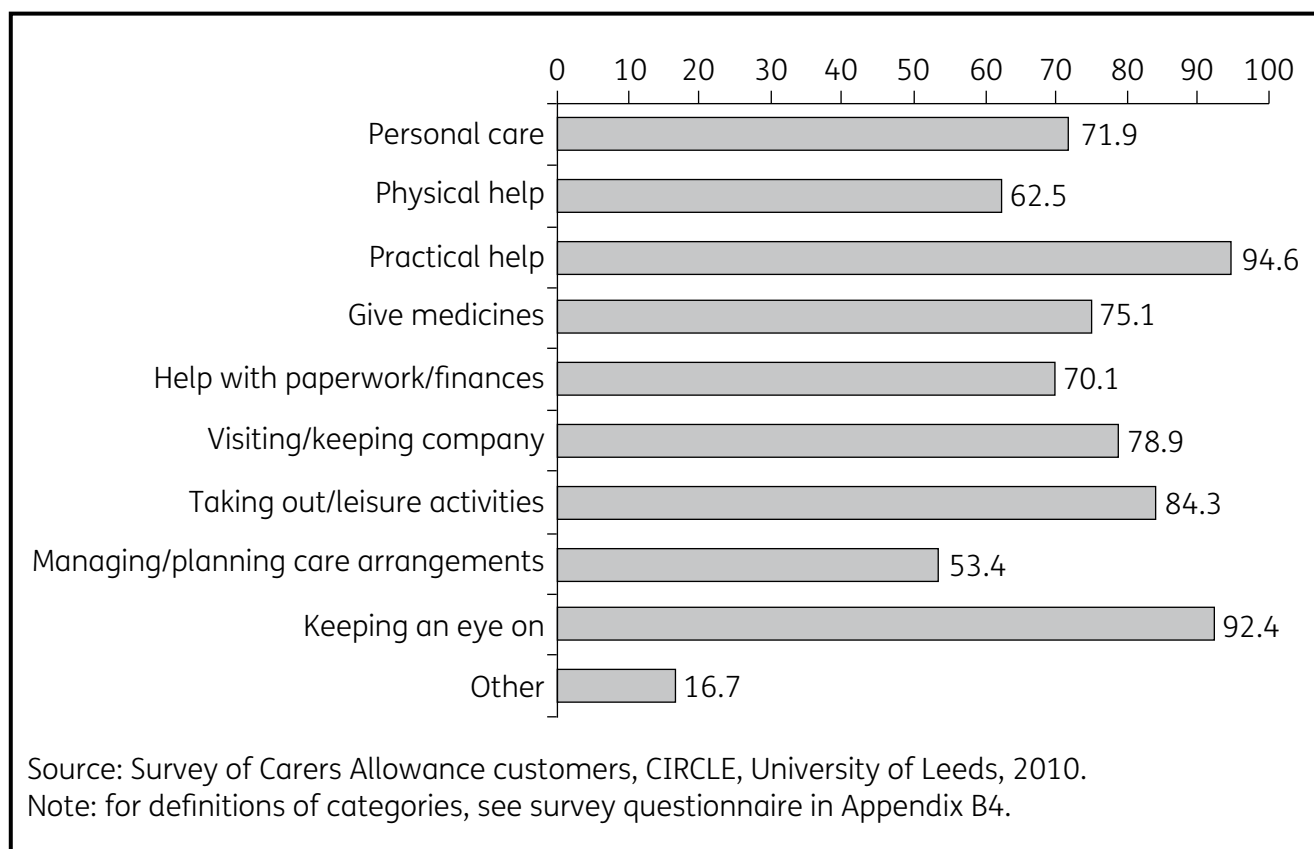
In the survey, almost all respondents answered the question about how they were coping financially (summarised in Table 5.1). A large group (39 per cent) said they were 'just about getting by' and one in five said they were 'doing all right'. Only three per cent reported that they were, in financial terms, 'living comfortably'. Almost four in ten reported financial difficulties (about 20 per cent 'finding it quite difficult', and a similar percentage 'finding it very difficult' to manage financially).

Those carers who were finding it 'difficult' or 'very difficult' financially were more likely to be caring for a parent (34 per cent, compared with 20 per cent of other carers, $p=0.001^{**}$), and less likely to be co-resident with the person they cared for (83 per cent, compared with 90 per cent of other carers, $p=0.028^*$). They were also significantly less likely than other carers to say they preferred not to have a paid job (93 per cent, compared with 81 per cent, $p=0.001$), and more likely to say they preferred to be in paid work (30 per cent, compared with 19 per cent of other carers, $p=0.015$). This emphasis on paid work was echoed in the forums and interviews, where carers experiencing financial strain tended to see paid employment as the only realistic solution to their financial difficulties.

The type of care provided by survey respondents is shown in Figure 5.1. Very high proportions of respondents provided practical help (95 per cent), needed to 'keep an eye on' the cared for person (92 per cent), and supported their leisure activities (84 per cent). Almost three-quarters (72 per cent) were providing personal care. Even the type of support reported by the fewest respondents, 'managing/planning care arrangements' was indicated by more than half (53 per cent).

More detailed analysis showed that women were significantly more likely than men to provide personal care (78 per cent compared with 58 per cent, $p<0.001$), but that there was no statistically significant difference for this variable by age or BAME group. Men were more likely than women to provide practical help (99 per cent compared with 92 per cent, $p=0.001$) and more likely to provide physical help (76 per cent compared with 58 per cent, $p<0.001$).

Older carers (aged 50+) were more likely than younger carers (aged 16-49) to provide physical help (68 per cent, compared with 57.5 per cent, $p=0.016$), and they were also more likely than younger carers both to provide help with paperwork and finances (80 per cent, compared with 62 per cent, $p<0.001$), and to be involved in managing/planning other care arrangements (59 per cent compared with 48 per cent, $p=0.012$).

Figure 5.1 CA survey respondents by type of care provided

Carers' age, gender or ethnicity was not statistically significant for giving medicines, visiting/keeping company, for supporting leisure activities, or for 'keeping an eye on' the cared for person. White British carers were significantly more likely than BAME carers to provide physical care (65.5 per cent compared with 52 per cent, $p=0.014$).

As is well documented elsewhere, providing care on a long-term basis and for many hours a week through multiple tasks (the situation of the overwhelming majority of CA customers in the study), has a negative effect on carers' health (Yeandle *et al.*, 2007a; 2007c). In this study, only half (50 per cent, 246 respondents) of the carers surveyed said their health was 'fairly good', with around a quarter saying their health was 'good' (24 per cent, 122 respondents). Those who reported their health as 'not good' (132) represented 26 per cent of respondents. Not only is this very much higher than the figure seen in the general population (2001 Census) among people of working age who have no care responsibilities (eight per cent)²⁸, it is also considerably higher than the figure in the 2001 Census²⁹ for all carers who provide 50+ hours of care per week (17 per cent) (Buckner and Yeandle, 2005). Health among CA customers who responded to this study is thus considerably worse than for working age people in general and is also worse than that found in the wider group of people caring intensively on a regular basis³⁰.

²⁸ It should be noted that 65 respondents (approximately 12 per cent) in this study were not of working age (aged 60+).

²⁹ As Census data on carers does not differentiate those claiming CA, this is the best figure available for comparative purposes.

³⁰ Put another way, 74 per cent of CA customers in the survey expressed good or fairly good health compared to 92 per cent of people in the general population of working age with no caring responsibilities and 83 per cent of carers of working age who provide 50+ hours of care per week.

Health issues were discussed with CA customers in the forums and interviews, revealing a variety of health-related problems. Some described problems which had arisen as a direct consequence of the care they provided (depression, exhaustion due to lack of sleep, etc.); others spoke about health problems which affected and complicated their caring role (bad backs, diabetes, heart problems, cancer). Many carers reported in the forum discussions that their caring situations were exacerbating existing health problems.

The majority of carers in the study were caring for a relative in one of three categories: a disabled child (aged under 20); a spouse or partner; or a parent/parent-in-law (see Tables 5.3 to 5.5). Men in the study were considerably more likely than women to be caring for a spouse/partner, while women were considerably more likely than men to be caring for a sick or disabled child (in both the 'adult child over 20' and 'child under 20' categories) (see Table 5.3). The profile of carers' relationships with those they cared for in the CA survey data was very similar to that for all DWP CA customers in the UK (see Figure 5.2).

A little under one third (29 per cent) of respondents **cared for a child aged under 20**. When compared with carers of other people, these carers of disabled children were more likely to be:

- female (88 per cent were women, compared with 61 per cent, $p<0.001$);
- young (77 per cent were aged 16-24, compared with 43 per cent, $p<0.001$); and
- long-term carers (84 per cent had been caring for 2+years, compared with 57 per cent of other carers, $p<0.001$).

Almost a quarter (24 per cent) of the CA survey respondents **cared for a person aged 70 or older**. These carers were significantly more likely to be older themselves; 60 per cent were aged 50+, compared with 43 per cent of carers caring for younger people, $p=0.001$). However, they were also significantly less likely to be long-term carers (56 per cent had been caring for five years or more compared with 72 per cent of other carers, $p=0.002$).

Older carers (aged 50+) were more likely than younger ones to be caring for a spouse or adult child, while younger carers were considerably more likely to be caring for a child under the age of 20 (see Table 5.4). Those caring for a sick or disabled child under 20 were significantly more likely to report financial difficulties than other carers ($p=0.041$).

Table 5.3 CA survey respondents: relationship to person cared for, by gender

| | Main person for whom most care is provided is the carer's: | | | | | | | Number |
|-----------------|--|----------------------|------------------------------|----------------|-------------------|----------------------|-------------|--------|
| | Child/ grandchild | Spouse or partner | Parent/ parent- in-law | Adult child | Other relative | Friend/ neighbour | Grandparent | All |
| Gender n=474 | | | | | | | | |
| Male | 18 | 69 | 41 | 4 | 6 | 8 | 2 | 148 |
| Female | 127 | 54 | 73 | 36 | 24 | 5 | 4 | 323 |
| Total | 145 | 123 | 114 | 40 | 30 | 13 | 6 | 471 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

Table 5.4 CA survey respondents: relationship to person cared for, by age

| | | | | | | | | Number |
|-------------------|--|----------------------|------------------------------|----------------|-------------------|----------------------|-------------|--------|
| | Main person for whom most care is provided is the carer's: | | | | | | | |
| | Child/ grandchild | Spouse or partner | Parent/ parent- in-law | Adult child | Other relative | Friend/ neighbour | Grandparent | All |
| Age band n=489 | | | | | | | | |
| 16-49 | 113 | 38 | 65 | 13 | 15 | 8 | 5 | 257 |
| Over 50 | 34 | 92 | 53 | 28 | 16 | 5 | 1 | 229 |
| Total | 147 | 130 | 118 | 41 | 31 | 13 | 6 | 486 |

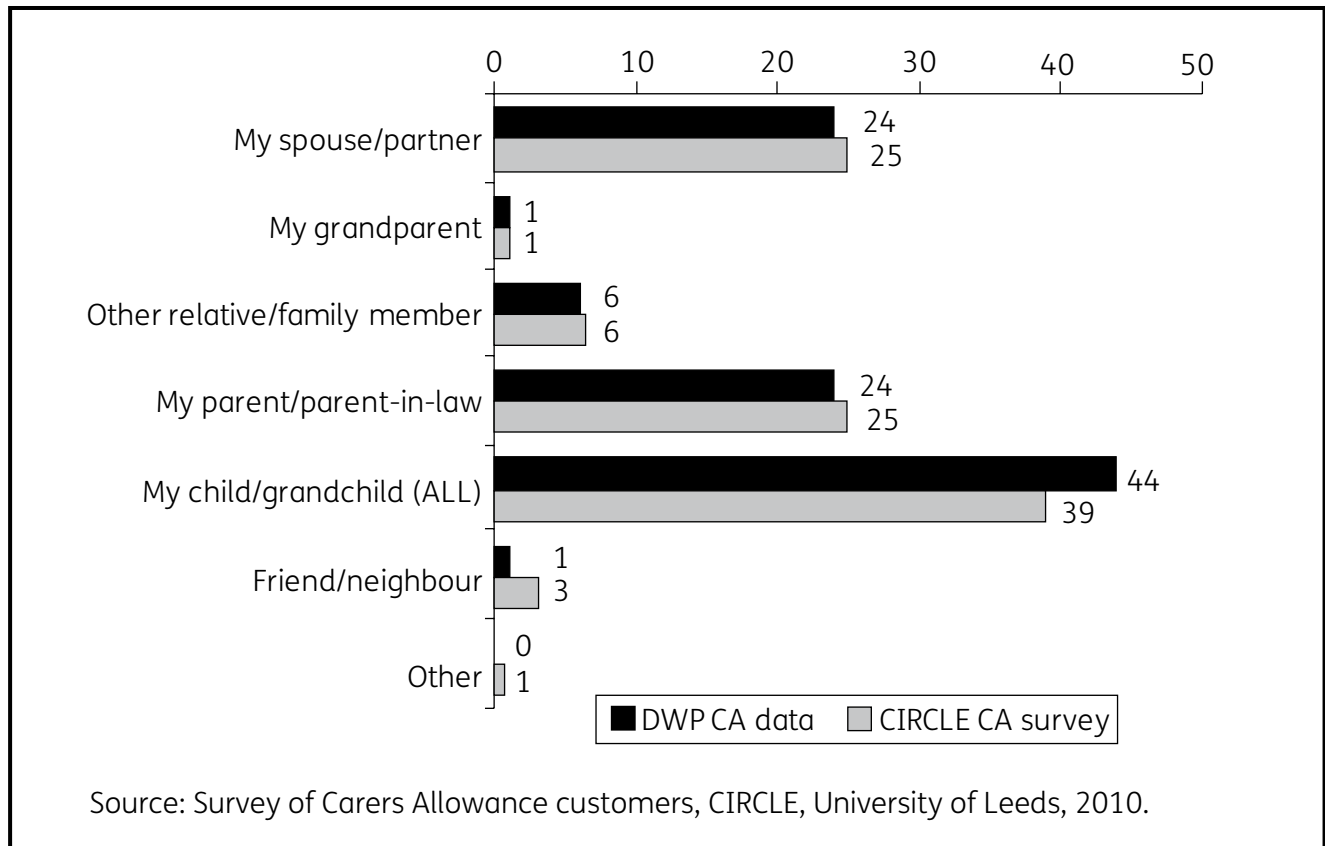
Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

Table 5.5 CA survey respondents: relationship to person cared for, by ethnicity

| | | | | | | | | Number |
|---------------------|--|----------------------|------------------------------|----------------|-------------------|----------------------|-------------|--------|
| | Main person for whom most care is provided is the carer's: | | | | | | | |
| | Child/ grandchild | Spouse or partner | Parent/ parent- in-law | Adult child | Other relative | Friend/ neighbour | Grandparent | All |
| Ethnicity n=489 | | | | | | | | |
| White British | 109 | 109 | 94 | 34 | 24 | 9 | 3 | 382 |
| All other groups | 38 | 21 | 24 | 7 | 7 | 4 | 3 | 104 |
| Total | 147 | 130 | 118 | 41 | 31 | 13 | 6 | 486 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

Figure 5.2 Relationship to person cared for: CA survey and DWP data



Compared with carers of other people, carers of a spouse were more likely to be:

- aged 35 or over (93 per cent, compared with 83 per cent, $p=0.003^{**}$);
- men (56 per cent, compared with 23 per cent, $p<0.001^{***}$);
- living in the same household as the person they care for (99 per cent, compared with 83 per cent, $p<0.001^{***}$);
- caring for one person (97 per cent, compared with 86 per cent, $p<0.001^{***}$); and
- living in a household containing fewer than three people (79 per cent, compared with 63 per cent, $p=0.001^{**}$).

For this group, there was no statistically significant difference in health, finances, whether they were in employment, whether they gave up work to care or whether they would prefer to be working. However, there were statistically significant differences in economic activity, with carers of a spouse more likely to be 'retired' (17 per cent compared with three per cent) or permanently sick or disabled themselves (five per cent compared with one per cent). Among those who had given up work to care, carers of a spouse were less likely than other carers to say they had given up work because they were unable to negotiate different working hours (eight per cent, compared with 26 per cent, $p=0.004^{**}$).

Compared with carers of other people, carers of a child were more likely to be:

- aged under 50 (67 per cent, compared with 44 per cent, $p<0.001^{***}$); and
- women (88 per cent, compared with 56 per cent, $p<0.001^{***}$);

- living in the same household as the person they care for (98 per cent, compared with 81 per cent, $p<0.001^{***}$);
- caring for more than one person (18 per cent, compared with seven per cent, $p<0.001^{***}$);
- living in a household with three or more people in it (53 per cent compared with 19 per cent, $p<0.001^{***}$); and
- in paid employment (13 per cent compared with seven per cent, $p=0.03^*$).

There was no significant difference, however, in health, finances, whether they gave up work to care or whether they would prefer to be working.

Of those who had given up work to care, compared with carers of other people, carers of a child were:

- more likely to have given up work because they were unable to negotiate their working hours (32 per cent, compared with 15 per cent, $p=0.004^{**}$); and
- less likely to have given up work because they needed more time to manage caring (57 per cent, compared with 81 per cent, $p<0.001^{***}$).

One of the discussion forums comprised carers of a sick or disabled child ($n=11$). Most carers in this group felt that care-related support, including CA, was in need of revision to meet their needs. In a separate forum discussion, one carer (female carer; forum: new to CA) pointed out that the onset of caring for a child is often unexpected, and usually happens to the carer at an early age (unlike caring for an elderly parent, which is more often anticipated and tends to occur later in the carer's life). This carer's view was that CA had been designed many years ago as a benefit to support older carers to care for a sick or disabled spouse, but was now out-of-date and inadequate in meeting the everyday life needs of carers of sick or disabled children. She pointed out that in the past, many sick and disabled children did not live long enough to require care, but that medical advances meant more disabled children were now surviving and requiring longer term care. She argued that both CA and local care and support services needed to evolve to take this group of carers into proper consideration.

Other parent carers observed that some conditions affecting sick and disabled children had only relatively recently been identified (e.g. Asperger's Syndrome), and felt carers of children with these conditions were not adequately supported by the care services available, sometimes leaving them exasperated:

'The problem is that [my son] is not physically disabled and he's not 100 per cent mentally disabled...They find it really difficult for where he fits, and that's always been the problem. He doesn't...fit in any of their little boxes.'

(Female interviewee, caring for an adult child)

Compared with carers of other people, carers of a parent were more likely to:

- report financial difficulties (54 per cent, compared with 36 per cent, $p<0.001^{***}$); and
- live in a household with fewer than three people in it (79 per cent, compared with 63 per cent, $p=0.002^{**}$).

However, they were less likely to be:

- caring for 100+ hours per week (29 per cent, compared with 52 per cent, $P<0.001^{***}$);
- long-term carers (five+ years) (49 per cent, compared with 74 per cent, $p=<0.001^{***}$); and
- living in the same household as the person cared for (67 per cent, compared with 94 per cent, $p<0.001^{***}$).

In this group (carers of a parent) there was no significant difference, compared with other carers, in health, or whether they gave up work to care. Among those not in paid work, carers of a parent were less likely than other carers to want to be in paid employment (16 per cent, compared with 26 per cent, $p=0.05^*$), and among those who had given up work to care, carers of a parent were more likely to have given up work because they needed more time to manage caring (85 per cent, compared with 68 per cent, $p=0.02^*$).

The interviews with people caring for an older person and the discussion forum composed of carers of an older person (almost always a parent) revealed that although these carers had more flexibility in their personal lives than many other carers (often, the person they cared for was not totally dependent on them), it was not always easy to persuade the cared for person to accept formal services. Frequently, the older person (feeling there was stigma attached to using formal services) resisted admitting that they needed this type of help. This could leave the carer in a difficult situation:

'There was talk, when the social worker came to my house, she spoke about maybe letting my mum go to a day centre and things like that, which I think might be a good thing, because she's meeting people her own age and she's having a chat, things like that. And they also spoke about respite, but mum got really annoyed and said nasty things about me – if I put her in respite for a little couple of days or something, 'I'm not going in a home', and all that business. But I'd never said she should!'

(Female interviewee, caring for a parent)

The BAME carers in the study were considerably less likely to be caring for a spouse or an adult child than White British carers (see Table 5.5). This is probably related to their age. BAME carers in the study were statistically more likely ($p=0.002$) to be young (compared with White British carers – 66 per cent of BAME carers were aged 16–49 years and 34 per cent were over 50; whereas for the White British respondents the figures were 49 per cent and 51 per cent respectively).

Further data from the CA survey revealed that while over 85 per cent (429) of respondents cared for one person, almost ten per cent (48) cared for two people, two per cent (ten) cared for three people; and just under one per cent (four) cared for four people. Compared with carers who were caring for one person, multiple carers were significantly more likely to be:

- female (83 per cent, compared with 67 per cent, $p<0.011^*$);
- from a BAME group (34 per cent, compared with 21 per cent, $p<0.033^*$);
- caring for a child (61 per cent, compared with 35 per cent, $p<0.001^{***}$); and
- providing personal care (85 per cent, compared with 70 per cent, $p=0.014^*$).

However, they were less likely than other carers to be caring for a spouse or partner (seven per cent, compared with 29 per cent, $p<0.001^{***}$).

Most survey respondents (85 per cent) lived in the same household as the person they cared for, and two per cent said that they sometimes lived in the same household as the person they cared for. Compared with carers who were not co-resident with the person they cared for (a much smaller group, 13 per cent of respondents), co-resident carers were significantly more likely to be:

- caring for a spouse or partner (30 per cent, compared with three per cent, $p<0.001^{***}$);
- caring for a child (43 per cent, compared with six per cent, $p<0.001^{***}$);
- long-term carers (five+years) (71 per cent, compared with 39 per cent, $p<0.001^{***}$);

- providing 100+ hours of care per week (52 per cent, compared with nine per cent, $p<0.001^{***}$);
- people who had left work to care (60 per cent, compared with 38 per cent, $p=0.007^{**}$);
- giving medicines (77 per cent, compared with 61 per cent, $p=0.008^{**}$); and
- claiming DLA (24 per cent, compared with three per cent, $p<0.001^{***}$).

However, they were less likely to be:

- caring for a parent (19 per cent, compared with 64 per cent, $p<0.001^{***}$);
- having financial difficulties (38 per cent, compared with 53 per cent, $p=0.028^{*}$);
- claiming Housing Benefit (44 per cent, compared with 61 per cent, $p=0.015^{*}$);
- claiming Income Support (48 per cent, compared with 64 per cent, $p=0.016^{*}$); and
- visiting/keeping company (77 per cent, compared with 92 per cent, $p=0.005^{**}$).

In the forums and interviews, carers reported that they supported people with a very wide range of conditions. Some carers noted that some conditions required them to spend considerable sums on items (such as specialised equipment) which they felt were not adequately covered either by their CA payment or any funds available to the person they cared for.

Some forum participants and interviewees pointed out that the condition of the person they cared for meant they were carrying out tasks which would otherwise have to be performed by medically qualified staff; others said their main role was to be present to take care of the cared for person in case anything occurred which required their assistance. This evidence indicated that, because of the variety of caring roles and duties, it is far less practical for some carers to work part-time or access alternative care support services than it is for others (see also Chapter 6). Conditions which involve unpredictable episodes (such as epilepsy) were particularly difficult to manage. One carer noted that carers could never predict when an episode might occur and had to be permanently prepared to deal with them. Some carers in this situation found it difficult to ever plan a holiday, a break or even a shopping trip, always feeling they had to be available to respond if needed.

Carers contributing to the forum discussions seemed very conscious of how they were treated by society at large. Some of those caring for close relatives (children, parents or partners) felt that other people (or 'society' in general) 'resented' the fact that they received state funds and support. In one forum, carers discussed sometimes feeling that others 'resented' the financial support they received. One, who cared for a friend, believed that those caring for someone outside their family were less likely to experience this. Others in the forum (all caring for family members) agreed, arguing that caring for a friend or neighbour was more likely to be viewed as 'warranting' financial compensation, whereas those caring for family members were expected to provide their care as a matter of responsibility.

5.2 How Carer's Allowance is spent

The survey asked carers what they spend CA on (see Table 5.6). The large majority (approximately 70 per cent) incorporated CA into their weekly household budgeting. Others said they used CA for regular caring expenses³¹ (17 per cent of respondents) and travel costs (eight per cent), as shown earlier in Table 4.3. Men were less likely than women to use CA on regular care expenses, but more likely to use it for general household expenses. There were no significant differences by ethnicity, length of time caring or length of time on CA.

Table 5.6 CA survey respondents: how CA is spent, by gender

| | Gender (n=448) | | | | Total | |
|---------------------------------------|----------------|------------|------------|------------|------------|------------|
| | Male | | Female | | | |
| | % | numbers | % | numbers | % | numbers |
| Weekly income/general expenses | 76 | 104 | 67 | 209 | 70 | 313 |
| Regular care expenses | 14 | 19 | 18 | 57 | 17 | 76 |
| Travel costs | 5 | 7 | 9 | 27 | 8 | 34 |
| Emergencies | 1 | 2 | 4 | 11 | 1 | 13 |
| Holidays/breaks | 1 | 1 | 2 | 6 | 1 | 7 |
| Recreational/social activities | 2 | 3 | 0 | 1 | 2 | 4 |
| Cover costs of caring if carer is ill | 1 | 1 | 0 | 0 | 1 | 1 |
| ALL | 100 | 137 | 100 | 311 | 100 | 448 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

Table 5.7 reveals a few differences in how CA is spent between carers who expressed different degrees of managing to cope financially: carers who were generally coping financially were more likely than carers finding it difficult to spend CA on regular care expenses and to include it as weekly household income. However, there was no statistically significance difference between any of these groups, so differences in financial status did not impact greatly upon respondents' use of CA.

When the forum respondents were asked if there was anything in particular they spent CA on, most suggested that the benefit was too small an amount to be set aside or to be used for a particular purpose other than some caring expenses and some travel costs. Most claimed that the money was simply fed into the weekly household budget and was spent on food and bills.

'It's not a lot of money – what can you do with it?'

(Female carer; forum: LLTC)

'It just goes into everyday household things really. It's not enough for anything else, is it?'

(Female carer; forum: child)

³¹ Based on discussion in the forums and the interviews, 'regular care expenses' include non-prescription medications, specialist equipment for the cared for person (unavailable to buy other than privately), subscription/admission fees to recreational services for the cared for person, and parking fees to attend hospital appointments.

Some carers in the study noted that their weekly CA payment arrived at the same time as their other state benefits, and that they had never considered it as separate from other income they received. Others claimed that CA was spent on care-related expenses such as transport for themselves and the cared for person, high heating and electricity bills run up as a consequence of the cared for person's disability (for instance, additional washing of clothes for sick and disabled children), and any specialist equipment needed to assist in the caring situation³².

'My daughter's got two different sized feet, so I've got to buy two different pairs of shoes every time she needs a new pair of shoes. It is hell, because she's got to wear, not only has she got two different sized feet, if she wanted an ordinary pair of shoes, I've got to buy them. Because she's weak down one side on her body, she wears a splint, which is another size bigger than her foot anyway. So I've got to buy two pairs of shoes, which is 70, 80 quid a time, and 50 quid is not going to go anywhere near.'

(Female carer; forum: seeking work)

Table 5.7 CA survey respondents: how CA is spent, by financial status

| | Living comfortably | Doing all right | Just about getting by | Finding it quite difficult | Finding it very difficult | Don't know | Total |
|---------------------------------------|--------------------|-----------------|-----------------------|----------------------------|---------------------------|------------|------------|
| Numbers | | | | | | | |
| Weekly income/general expenses | 8 | 56 | 123 | 64 | 68 | 5 | 324 |
| Regular care expenses | 4 | 11 | 34 | 18 | 10 | 1 | 78 |
| Travel costs | 1 | 5 | 12 | 6 | 8 | 1 | 33 |
| Emergencies | 1 | 2 | 5 | 3 | 2 | 0 | 13 |
| Holidays/breaks | 0 | 4 | 2 | 1 | 0 | 0 | 7 |
| Recreational/social activities | 1 | 0 | 2 | 1 | 0 | 0 | 4 |
| Cover costs of caring if carer is ill | 0 | 0 | 0 | 0 | 1 | 0 | 1 |
| ALL | 15 | 78 | 178 | 93 | 89 | 7 | 460 |
| Percentages | | | | | | | |
| Weekly income/general expenses | 53 | 72 | 69 | 69 | 76 | 71 | 70 |
| Regular care expenses | 27 | 14 | 19 | 19 | 11 | 14 | 17 |
| Travel costs | 7 | 6 | 7 | 6 | 9 | 14 | 7 |
| Emergencies | 7 | 3 | 3 | 3 | 2 | 0 | 3 |
| Holidays/breaks | 0 | 5 | 1 | 1 | 0 | 0 | 2 |
| Recreational/social activities | 7 | 0 | 1 | 1 | 0 | 0 | 1 |
| Cover costs of caring if carer is ill | 0 | 0 | 0 | 0 | 1 | 0 | 0 |
| ALL | 100 | 100 | 100 | 100 | 100 | 100 | 100 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

³² Disability Living Allowance (DLA), one of the qualifying benefits for people who are cared for by CA customers, is intended to help pay for such items. Some carers in the study felt these costs also fell on them as carers, and some incurred the costs mentioned in separate households (e.g. washing clothes or the costs of making regular visits to attend someone living elsewhere).

In a qualitative sample of 83 carers, only one forum respondent and two interviewees claimed they were able to set aside their CA for non-care-related purposes. One of these said CA was put towards an annual holiday for herself, her husband and the daughter they cared for. She felt relatively lucky, as her husband had a full-time job, allowing her to set aside CA in this way. In the other two cases, the CA was used to provide an occasional treat (new clothes, a meal, etc).

The interviews with carer advisers revealed that most found it difficult to identify what CA is spent on by carers. Their comments included that: CA is probably most commonly added to other household income to cover day-to-day living expenses; CA is felt to be too low to be budgeted for separately; and CA is probably often spent on care-related costs, such as transport, food – views which were consistent with data in the survey. One carer advisor also pointed out that how CA is spent depends not only on individual circumstances, but also on what other carer support is available. As different levels and types of support are provided by local authorities, some carers may need to spend CA on items which others may be able to obtain with local authority support³³.

Respondents in the forums and the interviews reported that CA was a crucial source of their household income. Unable to work full-time and in some cases having no other source of personal income, most carers reported that they would not be able to get by without CA. Only a very few respondents claimed they could survive financially without CA; these were carers who had a partner or spouse bringing a full-time wage into the household. Only in these cases could CA be used for breaks, holidays, or for treats for either those they cared for or themselves.

Although CA was mainly used as general household income, this conflicted with some carers' belief that CA should be a sum they could spend on themselves:

'Sometimes I feel like it should spent on maybe me – getting my hair cut or something like that, buying a new dress or something like that. But it's not going to happen, and I'm sure nobody else uses it for those things...maybe a few years ago you might have been able to – but now people just need that money just to get through the week.'

(Female interviewee, caring for a parent)

Some respondents nevertheless expressed a wish to be able to spend their CA on themselves. Items they would have liked to spend it on included a basic meal at a restaurant or pub – one saying *'Once a month so you can feel like you're alive!'* (male carer; forum: LLTC), or using it to contribute to an annual holiday. Few felt this was possible, however. It was frequently argued that everyday household costs ought to be covered by other benefits, with CA an individual 'reward' for caring efforts, in acknowledgement of their caring role and the social contribution they made.

Other respondents had a rather different attitude, seeing CA is a 'wage replacement' benefit and feeling it should be sufficient to cover all household costs and allow families to prepare, financially, for their future needs.

³³ Differences in carer support provided at local level are considered in the 'Carers in the Region' profiles (nine profiles of the English regions) commissioned by the Department of Health (Buckner et al., 2010).

5.3 Carers' perceptions of how Carer's Allowance affects them in their everyday lives and decision-making

Some CA customers expressed views on CA and how claiming CA affected them in their everyday lives. A brief overview of their opinions is included here. The points raised mostly confirm the findings of other research (HoC PAC, 2009; NAO, 2009; Hawkins *et al.*, 2007; Arksey *et al.*, 2005) and are not discussed in greater detail as it was not the purpose of this study to replicate such work. In the discussion forums and interviews (83 carers taking part), the main points made on this theme, sometimes with great strength of feeling, are set out below.

Low income affected carers in their everyday lives, compromising their dignity and exposing them to poverty, stress and feelings of low self-worth. Having to manage on an income which was much lower than before caring began could be both difficult and demeaning (see Section 5.2). Some felt the value of the maximum weekly CA payment was far too low.

The maximum earnings limit (before CA is removed) limited carers' access to reasonably paid work. Carers felt this exposed them to low-skilled, low paid work if they tried to combine work and care.

'If you want to work and still qualify for your Carer's Allowance, then you have to de-skill and get a job [in] retail. So you get yourself de-skilled and once the caring role has ended, you have to do the same job because you've lost your training skills.'

(Female carer; forum: LT care)

'While I'm out at work, OK, they have to have a threshold. OK, I accept that. But why can't you earn a bit more, and your allowance goes down until you hit a level? And then, once you've got to that level, you've gone over and you don't get it [CA]. That's fine. But in the meantime, I'm basically penalised for working.'

Female carer; forum: working)

It could be difficult for carers to access study opportunities while claiming CA. Some felt frustrated and upset about this. Several also complained that caring would appear as a 'gap' in a carer's CV, even though care involved acquiring and practising a range of useful skills:

'Myself and my partner [are] both...at Uni., officially full-time students. And if you're a full-time student you can't claim CA. Even if you are juggling being a full-time student between each other, and dicing – you know, avoiding lectures and – your tutors know you're doing that because you couldn't be a full-time student otherwise. I still think it's unfair that you're not allowed that paltry amount of money. You know, it's another slap in the face.'

(Female carer; forum: seeking work)

*'Why not give a qualification for caring? Otherwise all the caring time in employment terms has been wasted. Courses, or something, would make one more employable [and carers can] get a caring certificate or something. There needs to be courses, or something that people could go on to prepare themselves for the future. There should be help for people.'*³⁴

(Male carer; forum: complex benefits)

³⁴ Jobcentre Plus introduced Care Partnership managers to work with Jobcentre Plus Personal Advisers to inform carers (including CA customers) of what links to employment are available locally in 2010, during the period in which this study was undertaken.

Complexity in the wider system of benefits and support was perceived by carers to be confusing and disruptive, in some cases 'muddling up' their lives. Some nevertheless argued for more discretion and flexibility, albeit with better co-ordination:

'They tell you that you can earn an extra £100 a week, after taking off things but, yeah, it might not affect your Carer's Allowance, [but it would] probably affect your Income Support, and then everything gets mucked up, doesn't it?'

(Female carer; forum: LLTC)

'Couldn't the government look at doing something where there's a small disability allowance and a severe disability allowance (for carers)? [...] there are some carers who get £50 for doing sweet FA, and there are other people who get £50 for working hard. [...] At the moment, it's £50 for whatever, whether a person has got one thing or another. I'm not trying to demean – but I do think there should be some kind of alternative system.'

(Female carer; forum: working)

Some carers felt that multiple, demanding caring responsibilities seemed not to be adequately recognised. Some expressed strong views about this:

'I think it should reflect work that you actually put in [...] You can't say that £53 is the compensation for the 17-18 hours that you're constantly on duty during the day. If you've something like – my daughter's out at the centre from 9 till 4, life permitting. That means 17 hours in the day, where I'm her guardian, I look after her and I'm up during the night. Then I have to be up during the nights – I have to be there for those 17 hours for transport, washing, bathing, dressing, whatever I'm doing for her. Somebody else may do less hours. You have a very, very heavy job, and it should reflect that. [...] It should encompass everything and reflect the work that you're putting in.'

(Female carer; forum: complex benefits)

Many carers felt it was difficult to find out what help is available and how to access it. This was a recurrent theme:

'I would say, for everybody who's actually claiming something like Carer's Allowance, there's got to be so many people who don't know about it and (are) not claiming it and just struggling along. Because they've not been told! People always just assume that you're somehow going to acquire this knowledge.'

(Female carer; forum: seeking work)

6 Carer's Allowance customers and paid employment

This chapter explores issues relating to paid employment for carers in receipt of Carer's Allowance (CA), considering how caring and work interact in their daily lives, how carers manage their caring roles alongside paid employment, and how the eligibility rules for CA impact on their decisions relating to work.

6.1 Carer's Allowance customers' employment circumstances

Most survey respondents (74 per cent of the women and 71 per cent of the men) described themselves as 'looking after their home and family full-time' (see Table 6.1). A tiny number (five carers) claimed to be in full-time paid work (two per cent of men, and less than one per cent of women), and about one in 12 respondents had a part-time paid job in addition to their caring role. This group was overwhelmingly female: 35 women (11 per cent of female respondents), compared with just three men (two per cent). By contrast, men significantly outnumbered women among those respondents who said they had 'retired' from paid work: 19 men (13 per cent of male respondents), compared with eight women (2.5 per cent of female respondents). More women than men (14 women, compared with four men) said they were actively looking for work or saw themselves as unemployed. Detailed analysis showed that male carers in the survey were statistically less likely than female carers to be in paid employment (four per cent compared with 11 per cent, $p=0.09^{**}$), but there were no statistically significant differences between those in employment/not in employment with respect to age, ethnicity, health and finances.

Table 6.1 Employment status of CA survey respondents

| Employment circumstances over previous 7 days | Men | | Women | | All | |
|---|-------|-----|-------|-----|-------|-----|
| | % | No. | % | No. | % | No. |
| Looking after family/caring FT | 71.4 | 105 | 74.2 | 241 | 73.3 | 346 |
| Full-time paid work | 2.0 | 3 | 0.6 | 2 | 1.1 | 5 |
| Part-time (<30 hrs) paid work | 2.0 | 3 | 10.8 | 35 | 8.1 | 38 |
| Looking for work/unemployed | 2.7 | 4 | 4.3 | 14 | 3.8 | 18 |
| Permanently sick or disabled | 4.8 | 7 | 1.5 | 5 | 2.5 | 12 |
| Retired from paid work | 12.9 | 19 | 2.5 | 8 | 5.7 | 27 |
| Student | 1.4 | 2 | 2.2 | 7 | 1.9 | 9 |
| Other | 2.7 | 4 | 4.0 | 13 | 3.6 | 17 |
| ALL | 100.0 | 147 | 100.0 | 325 | 100.0 | 472 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

The data on the CA survey respondents' economic activity differs quite markedly from data on all carers in the 2001 Census, which showed that among men of working age caring for 20-49 hours and for 50+ hours per week, about 63 per cent and 45 per cent respectively had some form of paid employment, compared with four per cent in the CA survey³⁵. For women, the Census figures showed that 52 per cent of those caring 20-49 hours, and 35 per cent of those caring 50+ hours per week were in some form of paid work (compared with nine per cent in the CA survey). Thus, the CA customers surveyed in this study were similar to the CA customers in official Department for Work and Pensions (DWP) data (see Table 4.2), and much more likely than the general population of carers with substantial caring roles to be outside paid work. While this is not surprising, it is of note from a policy perspective.

Table 6.2 Employed carers in the CA survey: summary of characteristics

| | Numbers | | |
|----------------------------|---------|-------|-----|
| | Men | Women | ALL |
| All in employment | 6 | 37 | 43 |
| Full-time | 3 | 2 | 5 |
| Part-time | 3 | 35 | 38 |
| Person cared for | 6 | 35 | 41 |
| Spouse or partner | 0 | 3 | 3 |
| Son or daughter | 1 | 22 | 23 |
| Parent | 1 | 8 | 9 |
| Other | 4 | 2 | 6 |
| Weekly hours of care | 6 | 33 | 39 |
| <35 | 1 | 4 | 5 |
| 35-49 | 2 | 6 | 8 |
| 50-99 | 1 | 12 | 13 |
| 100+ | 2 | 11 | 13 |
| Length of time caring | 6 | 35 | 41 |
| <1 year | 0 | 0 | 0 |
| 1 year up to 5 years | 3 | 11 | 14 |
| 5+ years | 3 | 24 | 27 |
| Financial circumstances | 5 | 37 | 42 |
| Living comfortably | 0 | 1 | 1 |
| Doing all right | 0 | 10 | 10 |
| Just about getting by | 2 | 17 | 19 |
| Finding it quite difficult | 1 | 6 | 7 |
| Finding it very difficult | 2 | 3 | 5 |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

The CA customers in the survey who were combining their care with paid employment (43 carers) were mostly caring for a son or daughter, although others were carers of a parent, spouse or other person (see Table 6.2). Many were caring intensively (26 for 50 or more hours per week), and most were long-term carers (five or more years). Ten of these carers said they were 'doing all right' financially, and one was 'living comfortably', but 12 were, despite their CA and their earnings from work, finding things 'quite' or 'very' difficult financially, and 19 said they were 'just about getting by'.

³⁵ Analysis of 2001 Census data in this passage is from Table 4, Buckner and Yeandle, 2006: 8.

This indicated that, in this study, very few of the CA customers combining work and care were gaining much financial benefit from doing so; most in this situation appeared to derive only modest financial benefit from having paid work (i.e. 31 out of 42 were, financially, finding it 'very difficult', 'quite difficult', or were 'just about getting by', see Table 6.2). Working carers in the qualitative sample mostly appeared to be 'keeping a foot in the door' of the labour market, or working for social or personal reasons. This finding differs from other evidence on combining work and care³⁶ (Yeandle *et al.*, 2007b) and showed that these carers were considerably better off than non-employed carers. This raises questions about whether the rules which restrict CA customers to earning no more than £100 per week from paid work while receiving CA may prevent them from gaining some of the benefits other carers obtain when combining work and care.

Table 6.3 Financial circumstance of CA customers: comparison of those in/not in paid employment

| | Not in paid employment | In paid employment | Total |
|---|------------------------|--------------------|---------------------|
| How well are you managing financially these days? | | | |
| Living comfortably | 13 3.2% | 1 2.4% | 14 3.1% |
| Doing all right | 65 15.9% | 10 23.8% | 75 16.6% |
| Just about getting by | 164 40.0% | 18 42.9% | 182 40.3% |
| Finding it quite difficult | 75 18.3% | 7 16.7% | 82 18.1% |
| Finding it very difficult | 88 21.5% | 5 11.9% | 93 20.6% |
| Do not know | 5 1.2% | 1 2.4% | 6 1.3% |
| Total | 410 100% | 42 100% | 452 100% |

Source: Survey of Carers Allowance customers, CIRCLE, University of Leeds, 2010.

The financial circumstances of CA customers in the study who were in paid employment are compared with those of customers not in paid employment in Table 6.3. When the data on each group was compared (on the question indicated) and subjected to relevant tests, the differences between the two groups shown in the table were not statistically significant.

With respect to (early) retirement, among the general male carer population of working age, only six to seven per cent had 'retired' (among all those caring 20+ hours per week), compared with 13 per cent of men in the CA survey; while among women, between two and three per cent (all carers 20+ hours per week) were 'retired', compared with a very similar figure (2.5 per cent) in the CA survey.

³⁶ Among carers in the 2007 CES survey, those in employment (who included 449 carers working full-time and 376 carers working part-time) were less likely, compared with those who had left work to care and those who were already outside paid work when caring commenced, to report facing 'a constant struggle to make ends meet' (31 per cent compared with 39 per cent and 44 per cent).

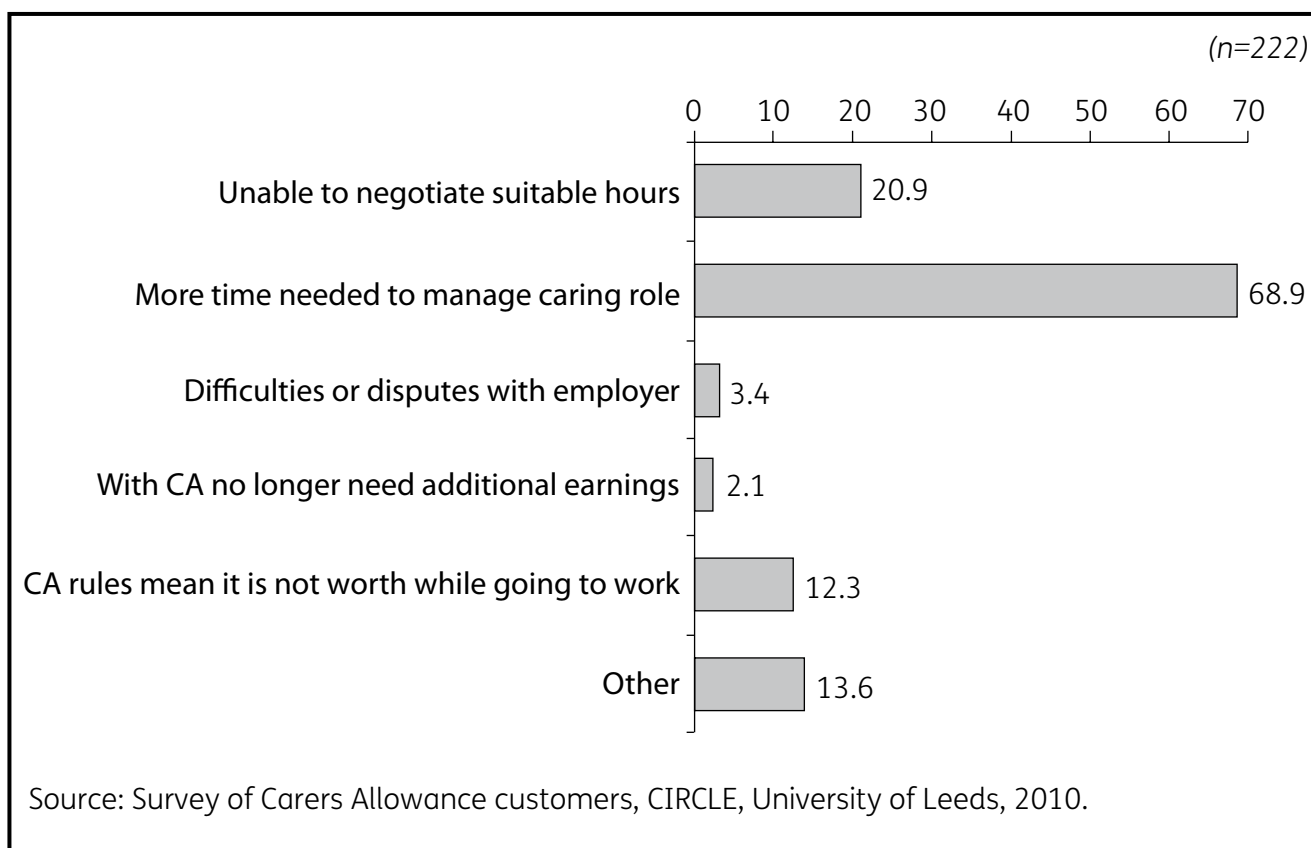
Permanent sickness/disability in the general male carer population of working age stood at ten per cent for those caring 20-49 hours per week and 17 per cent for those caring for 50+ hours per week (2001 Census data), compared with five per cent in the CA survey. Among women, 1.5 per cent of CA survey respondents described themselves as sick or disabled, compared with seven per cent of all women caring for 20-49 hours per week, and with ten per cent of all women caring for 50+ hours per week (2001 Census)³⁷.

The large proportion of CA survey respondents who were 'looking after home/family full-time' (73 per cent) compares with just nine per cent of male carers providing 20-49 hours per week of care, and 20 per cent of those caring for 50+ hours. The comparable Census 2001 figures for women were 29 per cent and 45 per cent. Comparison of the CA survey data with the 2001 Census thus shows that carers of working age in the general population are much more likely to be in paid work than CA customers in the survey. While it is not surprising (given the maximum earnings from paid work permissible for CA customers) that only very few survey respondents were in full-time work, comparison of the data on part-time work from the CA survey with Census data for those caring intensively shows that low employment rates among CA customers cannot be explained merely by the fact that they are (under the rules) caring for 35+ hours per week. The high proportion of CA customers defining themselves as 'looking after home and family full-time' may not be surprising, but this is not the usual self-defined status of most carers or working age (male or female) who provide 50+ hours of care per week; in 2001, 20 per cent of men caring for 50+ hours per week, and 45 per cent of women caring for 50+ hours per week gave 'looking after home and family full-time' as their main status (Buckner and Yeandle 2006). This raises the question of whether CA includes any disincentive to remain in or return to work, or if CA customers have other characteristics which make alternative statuses (e.g. employment or study) difficult.

Shedding some light on this, 395 CA survey respondents answered the question about whether they had given up work to care. Of these, 222 (56 per cent) said they had given up paid work to provide care. 168 of the remaining 173 (44 per cent) indicated what their economic activity was, and of these 162 (96.4 per cent) had already been outside the labour market when they had first become a carer, and six (four per cent) were still in paid work. Those respondents who had given up paid work had done so for a variety of reasons, as detailed in Figure 6.1. Most said they had needed more time to manage their caring role (69 per cent), but a minority (21 per cent) reported giving up work because they had been unable to negotiate suitable alternative working hours with their former employer. Very few (only two per cent) felt that receiving CA eliminated the need for additional earnings (Figure 6.1), but one in eight felt it was 'not worthwhile going to work', given the rules about income from paid work while claiming CA.

Exploring this in more detail reveals that women were significantly more likely than men to have given up a paid job because they were unable to negotiate suitable working hours (25 per cent compared with 12.5 per cent, $p=0.039$), as were carers of a sick or disabled child aged under 20 years, compared with other carers (36 per cent compared with 14 per cent, $p<0.001$). However, there were no statistically significant differences with respect to age, ethnicity, finances or health affecting giving up work to care.

³⁷ The lower rates of sickness and disability among CA customers could arise because people with long-term sickness or disability are mostly unable to care for another person for 35+ hours per week, although some disabled couples do care for each other, each receiving both disability and carers' benefits in their own right.

Figure 6.1 Carers who had given up work to care, by reason

Of the 384 survey respondents not currently in paid work who answered the question, 218 said that they had given up work to care (57 per cent). Men were significantly more likely than women to report giving up work because they needed more time to manage their caring role (80 per cent compared with 63 per cent, $p=0.007$); this explanation was also given more frequently by older (aged 50+) than younger (aged 16-49) carers (76 per cent compared with 63 per cent, $p=0.048$). Carers of older people (cared for person aged 70+) were also significantly more likely than other carers to have given up work because of needing more time (83 per cent compared with 62 per cent, $p=0.009$), while carers of a sick or disabled child aged under 20 were less likely to give this explanation (54 per cent compared with 76 per cent, $p=0.002$). While those from BAME groups were significantly less likely to have given up work to care (46 per cent compared with 59 per cent, $p=0.036$), there were no statistically significant differences for this variable by gender, age or health.

Of the carers in the study who were in employment ($n=44$), over half of these who responded to the question ($n=24$, 65 per cent) said they had altered their working hours because of their caring responsibilities, and 44 per cent ($n=14$) said they had altered their working hours because of the rules for claiming CA. Age, ethnicity and the health of the CA customer were not found to be statistically significant for this variable.

In Figure 6.2 the types of care provided by carers, according to whether or not they had given up work to care, are presented. This shows relatively minor differences between these two groups of CA customers. Nevertheless, detailed analysis indicates that, among carers who were not currently in work, those who had given up work to care were (compared with other carers) significantly more likely to be:

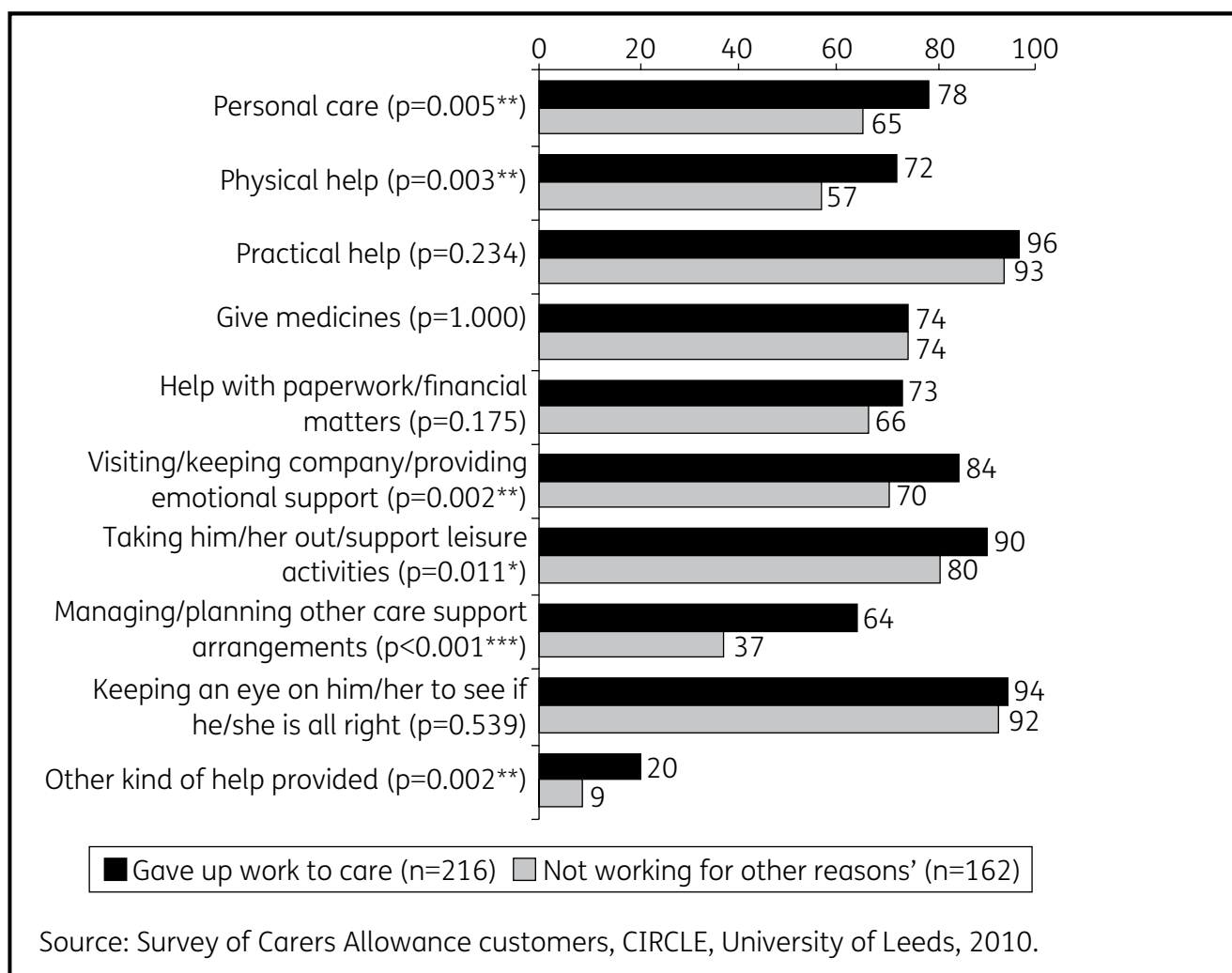
- providing personal care (78 per cent, compared with 65 per cent, $p=0.005^{**}$);
- providing physical help (72 per cent, compared with 57 per cent, $p=0.003^{***}$);
- visiting, keeping company or providing emotional support (84 per cent, compared with 70 per cent, $p=0.002^{**}$);
- managing and/or planning other care support arrangements (64 per cent, compared with 37 per cent, $p<0.001^{***}$);
- living in the same household as the person they care for (92 per cent, compared with 82 per cent, $p=0.007^{**}$); and
- living in rented accommodation (71 per cent, compared with 53 per cent, $p=0.001^{**}$).

The forums and interviews explored this aspect further, highlighting that for the carers in this part of the study, the commonest reason for leaving work to care was that, as they saw it, their caring responsibilities had simply become too great for work to continue. One explained:

'I took up a part time job about a year ago, it lasted three months. I reduced my hours and then reduced them again, and then I was only going in for a day and then it seemed to be that one specific day that all his stuff would happen at [her child's] school, and then eventually just – I mean they were trying to be as patient as possible with me but, unfortunately [...] it couldn't last.'

(Female carer; forum: complex benefits)

Figure 6.2 Type of care provided, by whether carer gave up work to care



In their detailed accounts, some carers said they had given up full-time work to take on a (different) part-time position, because they felt altering their hours in their previous full-time job to fit their complex caring roles would have been too difficult.³⁸

'Carer: Yes, I didn't actually suddenly stop work. What I did was I started taking jobs that fitted in with my son's school hours, and then a particular job that I was doing locally actually came to an end. It was only a temporary job and since then I just haven't looked, because the sort of work...I just really haven't looked since then.'

Interviewer: Because of the difficulties of combining work with caring?

Carer: Mainly that, yes, and also because, as I said, at the back of my mind I could really only work part-time anyway and then I've got a difficulty in the school holidays because I don't have any...My son's father works so he couldn't look after him and I don't have any family or friends in the area who could actually look after him, so I would have to make arrangements and obviously he's 14 and a half now, so it's not as if he needs a child minder but he does need somebody to be with him.'

(Female interviewee, caring for a child)

Others described a process of reducing their hours of employment before finally having to leave work and beginning a claim for either JSA or CA.

Some respondents in the study managed to combine work and care more easily than others. Those who took part in the forum comprising carers in paid work were very enthusiastic about combining work and care, highlighting the positive aspects of work more strongly than carers in the other forums (most of whom were out of paid work). However, by their own admission, most in this position felt that the reasons they were able to work were matters of good fortune, mentioning: the support of family and friends (who helped out with the care required); access to suitable alternative formal care facilities (or, for parents of sick or disabled children, suitable specialist schools); a job with flexible conditions and/or a sympathetic line manager; the close geographical proximity of their home and workplace. Even with a good package of services and the supports of peers in place, this group of working carers found their caring roles demanding alongside paid employment, although they were eager to retain their jobs because of the other benefits they gained from being employed (see Section 6.2).

Some carers related experiences of at first finding they could manage by cutting back their working hours, but later, as 'juggling' care and work became too much, or their employers were unable to continue to support them, finding it impossible to continue at work.

'If you're up in the middle of the night – how can you put 75 per cent of your concentration into work? My idea is, I was a catering manager and I was on £25,000 a year, it was really excellent money, and I did this all the time my husband was having his mouth operation... until unfortunately I had a breakdown. But I was getting up at five in the morning to go out to work at half past five in the morning and not getting home till six at night – and caring for my husband. And I had to give it all up unfortunately, to be there for my husband.'

(Female carer; forum: working)

³⁸ It was not possible to ascertain whether these cases occurred prior to the Work and Families Act 2006 which extended the right to request flexible working to some carers (HM Government 2006).

In the forums, some non-working carers said they intended to return to work at a later date, when their caring roles were less onerous. Some had already moved in and out of work during their caring roles, describing these changes as attempts to retain some form of professional life, use their skills, improve their financial situation, and sustain personal feelings of worth through social interaction – all of which, they felt, full-time caring problematised. Moving in and out of work was often a response to changed caring circumstances.

Employers, former and present, were generally depicted in a positive way by respondents, many of whom described them as sympathetic and helpful, ‘up to a point’. However, some carers had found their employment situation untenable, sometimes because their employer had hinted at increasing care-related problems (many carers claimed to understand their employer’s difficult position) or because they themselves felt guilty about not being able to fulfil their job role as they felt they should.

‘I started working part-time, kind of was reducing down rather than just stopping working, and I found that at the beginning [they] were OK, [but] after a period of time they started saying, “You really need to start thinking about this and what you’re doing”. Because they did get a wee bit stroppy after a while. It was just, for the first while it seemed to be, “That’s OK, that’s not a problem”, and I wasn’t off a lot because, at the end, I was only doing two and a half days a week anyway. But obviously there was the odd day where [cared for person] wasn’t fit and I had to be with him and [I would say], “Sorry, I can’t come in today”, which was not every week, it wasn’t. It’d be lucky if it was once a month. But once they just said, “You really have to stop some time” and I don’t know what changed, what happened, just all of a sudden it seemed to change.’

(Male carer; forum: complex benefits)

Several respondents claimed health problems brought on by their caring responsibilities, and/or their employer’s inability or unwillingness to allow them to work part-time, had led to their giving up work.

Other carers had needed to leave paid employment altogether. Those in this situation spoke of a ‘vicious circle’, in which once out of work, it became harder to find a new job – pointing out that carers with substantial caring roles lack the time and energy to apply for new jobs, and may have been out of the job market for so long that their skills are out of date. Box 6.1 illustrates one carer’s experience of this.

An important finding of the survey is that while the majority of respondents (around 70 per cent) were currently out of paid work, over 60 per cent said they would like to be in paid work once their caring role ends or permits this, and 23 per cent said they would rather be in paid work, alongside their caring responsibilities, now. Despite this, only a very small number (see Table 4.3) were looking for paid work at the time of the study (see Figure 6.3), and 14 per cent of those surveyed said they would prefer not to have paid work at all.

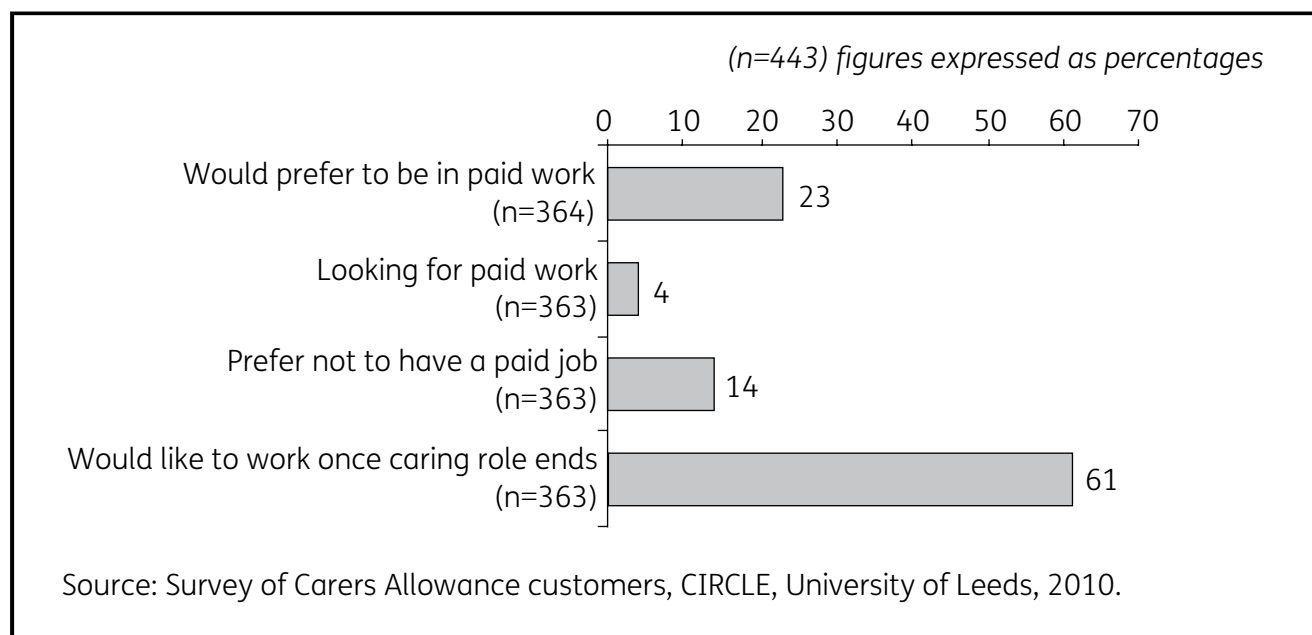
In the study, among those not in paid employment, White British carers were significantly more likely than carers from (all) BAME groups to be looking for work (5.3 per cent, compared with 0.1 per cent, $p=0.029$). Older carers (aged 50+) were significantly more likely to say they preferred not to have a paid job than younger carers (16–24) (21 per cent, compared with 8.5 per cent, $p=0.001$), perhaps not surprising as some older carers may have reached, or been close to, retirement age. Respondents who were caring for an older person (aged 70+) were significantly more likely than carers of younger people to say that they would like to have paid work once caring ends (78 per cent compared with 56 per cent, $p<0.001$).

Box 6.1 Moving from employment to Carer's Allowance

Jasper, who is over 50 years old, used to work at a major car manufacturing plant. He had been employed there for 22 years and was earning approximately £300 a week. He described this period as a 'good life'. For five years after this, he was unemployed and found it impossible to find work (because of his age and lack of appropriate up-to-date training). He was receiving JSA, but when his elderly mother became ill he switched his benefit package to CA and IS. Although Jasper has siblings, it was he who was expected to take up the care of their mother because he was out of work at the time. Jasper now feels 'trapped' in his caring role, with little or no opportunity to find work. He feels he is 'behind on his stamp contributions' which count towards his state pension, and considers this a major concern for the future.³⁹ He would like to get a job, for both financial gain and to achieve a renewed feeling of worth, but he does not see himself ever working again.

(Male carer; forum: new to CA)

Figure 6.3 Carers not in paid work: employment preferences



6.2 The significance of employment for Carer's Allowance customers

Many forum respondents and interviewees indicated that paid employment was important to them. Like the survey respondents, many expressed a desire to return to work in at least some capacity, citing a range of reasons why being able to work at the same time as providing care would be a positive step. (Some of the points made on this theme have already been outlined in Section 6.1.)

³⁹ It was not clear if this respondent was aware of the fact that, since 2002, if a person has spent a year on CA, a year's National Insurance (NI) contribution is credited to their NI record. The respondent was expressing his views in a forum prior to the introduction (on 6 April 2010) of Carer's Credit, a process which assists those who care for disabled people for over 20 hours per week, by contributing to basic State Pension and Additional State Pension (Directgov, 2010).

Forum participants often mentioned that combining work and care had, or would have, a positive impact on their mental health and well-being. For some, being employed offered a form of 'escape', allowing them to get away from their caring responsibilities, offering them an opportunity to meet other people, and as one put it, to *'have something just for themselves'* (female carer, forum: complex benefits). Several carers said that they had entered education or voluntary work for the same purpose. It was also often pointed out that work could enhance a carer's self-esteem. Paid employment offered carers the opportunity to be something other than a carer, and to gain fulfilment away from their caring role.

Carer 1: *'Yeah, but let's face it, when you do actually go out and do a bit of work, you're interacting with other people and you've got that normality.'*

Carer 2: *'Yeah, and you've got self-respect.'*

Carer 1: *'Yeah, [after I lost my job] it would have done me a lot of good just to have had that lifeline.'*

Carer 3: *'A bit of normality.'*

Carer 1: *'Yeah, and be with other people to take your mind off things.'*

(All were female carers; forum: working)

Some respondents claimed that, in the long-term, it was worthwhile and important to remain in touch with the workplace and maintain employment skills, so that a return to the workforce at a later date might be possible, perhaps after their caring role had ended.

'I've got a job there at the end of the day, even though I'm only doing one day a week. I can go back into full-time when anything happens. It's my [...] security. I can give the benefits up and know that I will still be able to pay my stamp and get my pension at the end of the day.'

(Female carer; forum: working)

Some carers felt working part-time while caring improved their future prospects. Several had ambitions to return to work full-time if and when their caring situation became less onerous.

'...my intention was that I would have [daughter] and have a little time off and go back at least part-time to the job I trained for, so at least I've trained. If I don't go back and do the job that I'm trained to do. And so I did feel that it was a complete waste that I'd done that, when I couldn't do it again. It was something I quite enjoyed and it was a natural progression.'

(Female carer; forum: complex benefits)

These carers felt it was important to demonstrate evidence of recent employment on their CVs. Many respondents also felt employers often did not understand or fully appreciate what carers did. They felt that, despite the many skills carers possess, caring did not confer any benefits in the job market, because employees do not recognise these skills as 'worthy'. Having a part-time job, respondents claimed, would help to fill the 'caring gap' in their CVs. The need to provide substantial care inevitably affected their long-term career aspirations, but they felt carers who remained at work part-time were more likely to maintain career-related aspirations. Working part-time also provided carers with opportunities to maintain skills, they felt, and to keep in touch both with workplace trends and with colleagues. Employment also provided a 'buffer' against present and future dependence on state benefits, and allowed them to maintain pension and National Insurance contributions.

Several (mainly younger) respondents mentioned feeling 'shame' or 'embarrassment' about relying on state benefits, and said they would much prefer to earn their own money. Younger carers also expressed considerable anxiety about their limited opportunities to establish a career.

In short, the great majority of respondents expressed a desire to have something else in their lives other than caring, and part-time work or education was frequently claimed to be the preferable option. Box 6.2 highlights a typical CA customer's view.

Box 6.2 CA customers' difficulties involved in accessing education

Polly and her partner attend university and have ambitions to apply for part-time jobs which will allow them to care for their autistic son without being in receipt of state benefits. Polly has high aspirations for her family's future and considers a successful education crucial to her long-term plans. Nevertheless, Polly is finding full-time study difficult, largely because she believes the CA study hours limit effectively forces her to claim CA only between academic terms. She finds the process of constantly having to switch on and off the benefit, at the same time as combining her caring role with education, extremely stressful. She claims that this has had a deleterious effect on her health. At the time of this study's discussion forum, Polly had recently returned to study at her university after three weeks of sickness brought on by exhaustion. During this period, her partner had to miss out on significant periods of his own education in order to care for their autistic son.

(Female carer; forum: Older Person)

6.3 Difficulties faced by Carer's Allowance customers in finding suitable paid employment

Finding a suitable job was often described by forum respondents and interviewees as a case of extreme good fortune, frequently involving flexible working conditions, a sympathetic line manager, a workplace geographically close to where the person cared for lived, and (often) successful arrangements for alternative care. This was very rarely achieved.

'Interviewer: So would you say those kinds of jobs are very rare to get hold of?

Carer: I would say impossible, which I tried to explain to the dole people. That's the sort of job I needed and they're talking...you have to go to this, I don't know what it's called, something Direct now and I'm saying, well, "I can be a dinner lady but..." – I was a dinner lady years ago, but I have to be in a school that's really close, that if my mum falls over or something I have to be able to go.'

(Female interviewee, caring for an adult child)

Some carers said that mental and physical health problems associated with social isolation increased their reliance on benefits, and some claimed that the longer a carer was out of work, the more difficult it was for them to find a job once their caring duties ended. This difficulty was reported to be a result of out-dated or 'rusty' work skills, loss of confidence, lack of experience, advancing age, and disconnection from networks of employment.

All these factors contributed to a tendency for carers to drop out of work and never return, leaving them reliant on benefits as a source of income for the rest of their lives.

'If I ever go back into the workplace, it makes me scared. That's such low money that you can earn, it's ridiculous, but I [...] it totally puts you off and when I'm starting to feel a little bit better and my goal is, if they get me off the steroids, then my conscience won't let me claim the benefits any more, I'm fit for work, part-time work. I can get part-time work, get good money to have a reasonable living. You accept it when you're not well because you're sitting on the thing feeling depressed, and you're not bothered about life anyway.'

(Female carer; forum: seeking work)

Respondents also felt that employers lacked an appreciation of the strengths which carers can bring to paid employment, and that this diminished the likelihood of carers being successful in job applications. Respondents reported that the difficulty of negotiating suitable hours of employment with employers further reduced the appeal of employment for CA customers. Arranging working hours so that they complied with both their existing caring responsibilities and the rules attached to the benefits they received meant taking into account variable shift arrangements and changes in salary (e.g. company bonus schemes and overtime). Carers said these additional difficulties added to their stress and undermined the possibility of successfully combining work with care.

Many carers felt the rules for CA reduce both the attractiveness and the feasibility of combining work and care. Many respondents said that their caring responsibilities forced them out of work, and that the difficulties of juggling caring responsibilities with existing employment were complicated by the rules of CA.

Respondents felt that CA rules affect their ability to secure work by placing very strict conditions on their employment possibilities. They considered there to be very few jobs available in the job market which allow carers to work, care and comply with the rules for CA. These rules were also seen as insensitive to the fact that, in order to work, a carer may be required to find someone else to look after the person they care for. Respite care, carers pointed out, is very expensive and the additional costs associated with it remove one of the principal reasons for working, especially if the alternative care costs more than the carer can realistically earn.

'You cannot afford to go to work, because you go to work and then you have to pay somebody else to look after that person while you're at work. It's like having a baby, I mean, I don't mind when he was little paying for the care, but now he's 25 I still have to pay for that care. [...] At the end of the day, I'm going out to work and I'm worse off than not going to work. [...] I want to go out to work, I want to do that. All they have to say is "Well, you can have your Carer's Allowance as well". But I can't.'

(Female carer; forum: seeking work)

The CA earnings limit was felt to reduce employers' appreciation of the strengths which carers can bring to paid employment, and to diminish the likelihood of carers being successful in job applications. Respondents reported that the difficulty of negotiating suitable hours of employment with employers further reduced the appeal of employment for CA customers. Arranging working hours so that they complied with the earnings rule was not only a question of fitting the wage to the earning threshold, but also meant taking into account company bonus schemes and variable shift arrangements. Carers said these additional difficulties added to their stress and undermined the possibility of successfully combining work with care.

Several carer advisers also felt the earnings limit for CA was too low, and that the sometimes ambiguous rules relating to what constitutes earnings (e.g. there was some debate as to whether Maternity Allowance could be classified as 'earnings') make carers' lives far more complicated than they are already. One carer advisor claimed that many carers felt financially worse off when

combining work and care. Similarly, several carer advisers claimed that limits on the amount of education or training in which a carer could participate before violating CA rules were a serious problem for many.

6.4 Non-employed Carer's Allowance customers

Not all forum respondents and interviewees expressed a desire to return to work. Some carers did not feel they could ever return to paid employment, in some cases because they had been caring for too long and had as a result developed very low career aspirations.

'My aspirations are quite low because, unfortunately [...] I had a career and I had to stop, and I know that I'll never go back to it and the only way that I could ever go back to work is if [her daughter] went into a care facility to live – and with her health problems, I couldn't do that because I know that she wouldn't. [...] Well, with the hospital appointments I have to know everything that is happening, I'm on the phone to them every day, finding out how the last day has gone...'

(Female carer; forum: complex benefits)

Others respondents, however, had little desire to work because they felt their caring responsibilities were too great to even consider combining these with paid employment. These carers often stated that their priority was to provide adequate care for the person they cared for. They resented official interventions which, they believed, were intended to pressurise them to return to work against their wishes. This was also noted by one carer advisor. While interventions aimed at helping carers combine work and care were viewed favourably by most, many respondents – both carers and carer advisers alike – stated that those carers who did not want to work should not be forced to do so.

7 Conclusions and recommendations

This study aimed to increase understanding of carers in receipt of Carer's Allowance (CA). It investigated how carers come to claim CA, carers' situation in relation to other state benefits, and their experiences in accessing CA. It focused particularly on the caring roles of CA customers, on how they cope with their daily caring responsibilities, and on how CA fits in with these roles, examining their experiences of paid employment, decisions concerning employment and/or education, and the role CA plays in these decisions.

The key findings from the study are summarised in this chapter and, emerging from this evidence, recommendations to inform policy developments are made.

7.1 Carer's Allowance: key findings

This study has shown that CA plays an important role in many carers' lives. It is a crucial source of income for those who find themselves in difficult caring situations, often with demanding responsibilities which limit their access to paid employment and/or education and training.

For many carers, however, CA is just one part of a complex package of support, drawn from a variety of sources, which enables them to fulfil their caring role and responsibilities. Other components of this support include other state benefits (e.g. Housing Benefit (HB) and Income Support (IS), including Carer Premium in appropriate cases), care services (e.g. respite/breaks services and the assistance of home care workers) accessed via local authorities or paid for privately, and informal networks of support (additional paid help from family and friends, either in a regular or occasional capacity).

Most carers in this study felt the current arrangements for CA were in need of significant change, although they pointed out that, to enable them to manage their caring responsibilities as they would wish, the whole system of support and services for carers needed to change as well. They wanted to see more sensitivity to their needs in the early stages of care, when carers often struggle to adjust to new and onerous circumstances. Very few of the carers in this study had an adequate appreciation of their rights in relation to Carers Assessment (conducted by their local authority), and few were aware of having been involved in such an assessment. Some carers felt that 'joined up' thinking between the different agencies involved in providing them with services and support (often mentioning services which are local authority responsibilities, such as Housing and Adults' and Children's Services) should be included. Most wanted more information on carers' rights and on accessible services, including CA, but felt this was not currently available to them.

For many carers in this study, becoming a carer was not a choice they had freely made or would have chosen. They frequently spoke of a moral obligation to provide support for (most commonly) a family member in need of care, and most were happy to enact this, within limits. As and when their caring situation had escalated, in many cases impacting on their capacity to continue in paid work and leading to poor health, applying for CA became necessary. Since carers almost universally rejected any view of themselves as 'unemployed', they welcomed the opportunity to apply for CA, which they felt was much more appropriate to their circumstances than Jobseeker's Allowance (JSA). Once carers had become aware of CA, they saw it as their only feasible option.

Nevertheless, the qualitative evidence in this study also showed that some carers felt uncomfortable about their situation and spoke about their sense that there was a stigma attached to receiving state benefits. This was compounded for some carers, particularly younger ones, by a feeling that the care they provided was part of their ordinary family lives – as parents, sons/daughters or as a spouse – and was part of their commitments and obligations to their family members. For these carers, accepting money for care felt in some way ‘wrong’, or socially embarrassing, even though they knew that they met all the criteria entitling them to claim CA.

Some carers had tried to survive financially for long periods, without applying for CA, because they anticipated many difficulties and frustrations in accessing this (or any other state support). However, when remaining in paid employment became untenable, usually after a caring situation had escalated, most had been faced with no choice other than to apply for CA.

Carers in this study had found that accessing CA involved a number of challenging stages. Seeking information and advice on the benefit had not always been easy, with many commenting on a paucity of available literature, and unsuccessfully approaching organisations which lacked adequate knowledge about it (e.g. Jobcentre Plus and healthcare centres), reiterating evidence in previous studies (Hawkins *et al.*, 2007). While the CA application procedure was seen by most in the study as quite straightforward, some resented having to, or had found it difficult to, present their caring situation in a way which would demonstrate that they qualify for CA. Many carers in the study had found the CA assessment procedure intrusive, and some felt they were on the receiving end of sceptical attitudes on the part of assessors which made them feel they were mistrusted. Many found the CA eligibility rules difficult to understand, and felt the way these were interpreted by assessors was inflexible, contradicting other evidence in the study in which Carer’s Allowance Unit (CAU) staff reported regularly trying to achieve the best outcome for the customer.

Once in receipt of CA, carers had commonly found themselves using it as part of their everyday household budgeting or for care needs (e.g. to pay utility bills, buy specialised equipment for the cared for person); it was very rare indeed for CA to be used for anything other than daily necessities (e.g. to pay for a holiday). Some carers in the study said that they would like to spend their CA payment on themselves (e.g. treat themselves to a break or a gift), but pointed out that this was simply unrealistic. Some saw CA as a ‘wage for caring’, others described it as a ‘token gesture’ from the government to compensate for their inability to work in the way they might prefer. In each case, carers in this study often felt bitter about what they perceived to be the low sum of money they received each week in CA payments, and many expressed the view that this indicated that they were undervalued by society at large.

7.2 Carer’s Allowance and different carers’ needs

In this study of CA customers, it was possible to explore and distinguish the circumstances and perceptions of carers in a number of different groups. These are summarised here, and are drawn on later in the chapter in the section on recommendations.

7.2.1 Younger and older carers

The present study has shown that younger carers (16–34 years old) have specific needs and perspectives which differ in some respects from those of older claimants. Younger carers were more likely to have been caring on a long-term basis (over five years); in many cases this was because they were caring for a child who had been in need of support from an early age.

Younger carers were more likely to have a paid job than other carers, and those who had been out of work at the time of the study were the group most likely to be seeking paid employment. This is not surprising given that many younger carers in the study also expressed a desire to develop careers once their caring responsibilities had either ended or become more manageable.

However, many respondents in the study (including older carers reflecting on younger carers' circumstances) claimed that this younger group of carers – particularly those caring for a child with a long-term condition – were the most likely to find it difficult to build a career, and the most likely to need to rely long-term on state benefits. The study showed that younger carers claiming CA were the group in the study most likely to be claiming two or more benefits, with many claiming Child Tax Credit, IS and HB as well as CA.

By contrast, older carers in the study particularly emphasised their concerns about what would happen when they reached State Pension age, and were no longer entitled to receive CA (as they perceived it). In the discussion groups and interviews, carers in this group, almost without exception, found this rule incomprehensible. Older carers were less likely than younger carers to want to enter/re-enter paid employment, probably because many were already near retirement age. They were also more likely than CA customers in other categories to provide physical help to the person they cared for, and to do paperwork for them.

7.2.2 Carers of a partner or spouse

Those who were carers of a partner or spouse were more likely to be men. They were also more likely to be aged over 35 years old, to be caring for just one person, and to live in the same small (three or fewer people) household as the person they cared for.

Carers in this group were also more likely to be (early) retired or to be permanently sick or disabled themselves; this may be related to the fact that male carers of a partner or spouse are likely to be older carers (aged 50+). The study found that many had given up work because they had been unable to negotiate suitable working hours which would enable them to provide the level of care needed.

There was some evidence in the study that carers of a partner or spouse were less likely than others to have in place formal care services; this was, for some, because they felt they could do a better job, and/or because their partner or spouse did not want anyone else to provide this care, but it is also likely to have been related to their greater difficulty in obtaining support through Adult Services, where support was, in most localities, restricted to only those in need of care formally assessed as 'substantial' or 'critical'.⁴⁰

7.2.3 Carers of a child

Our study showed that this group of carers was more likely than others to be female. The group was also younger (under age 50), and more likely already to have provided long-term care (five years or more). This is almost certainly because these carers were mostly mothers of children with a long-term condition.

⁴⁰ Under guidance issued by the Department of Health (DH) in *Fair Access to Care Services* (2003), local authority social workers completing assessments of a person seeking social care support must assess whether their needs are 'low', 'moderate', 'substantial' or 'critical'. Councils have local discretion about the level at which they will fund relevant support. DH replaced this guidance in February 2010, when *Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010* was issued. While the new guidance sets these criteria in a wider context, the same four categories of need continue to be used.

Carers of a child were the most likely to be in paid employment, possibly because they were also most likely to be women who were working part-time; it is possible that this group of carers had children in full-time education, giving them more time to work. Although this group was also the most likely to have a higher level of qualification (A level and above), since most jobs which fit in with the eligibility criteria for CA (concerning the upper earnings limit) are low paid and unskilled, many of these carers were, it seemed, working well below their skill level.

These carers were the most likely to report financial difficulties and the most likely to be claiming two or more state benefits; this is possibly related to the fact that carers of a child are the most likely to be living in the same household as the person they care for and to be caring for more than one person (and, therefore, also less likely to be in full-time paid employment). This group was also the most likely to feel that existing care services did not meet their needs.

Those in this group who had given up paid employment to provide full-time care most often explained that this was because they had been unable to negotiate suitable working hours; this may also be related to their child's condition, which often necessitated their constant supervision, or was highly unpredictable in terms of the illness or disability-related episodes involved.

7.2.4 Carers of a parent or older person

This group of carers was the most likely to be older themselves and was also less likely than other groups to have been caring on a long-term basis (five+ years). They were also the least likely to be providing very long hours of care (100+ hours per week), perhaps because the conditions of older people in need of care are often associated with ageing (e.g. frailty and early stage dementia) which involve a gradual decline rather than the periodic episodes associated with some conditions more common among younger disabled people.

Since carers of older people in this study were less likely than other carers to be living in the same house as the person they care for, it is understandable that they were the least likely to claim three or more state benefits. Nevertheless, they were also highly likely to report financial difficulties and, if they were currently outside the labour market, the most likely to say they would prefer to be in paid work. Since older people in need of care seemed to be the least likely to accept the services available from local authorities and/or private providers, their carers often found themselves providing most of the care, making seeking paid employment problematic.

7.2.5 Long-term carers and carers new to caring

In the study, there were significant differences between those CA claimants who had been caring on a long-term basis (five+ years) and those who were newer to caring. In the former group, the carers were more likely than newer carers to be female, to be aged 35-49, and to be caring for a child. Care of a child is, as discussed above, more likely than other forms of care to involve a long-term commitment. It also generally involves the carer living with the person they care for, as well as accessing multiple benefit packages; both of these were also more likely to be true of long-term carers.

Long-term carers were more likely than other carers to report that they were in poor health, and this was almost certainly because they were also more likely to provide very high weekly hours of care (100+ hours per week). The men in this study who provided long-term care were more likely than the women to provide practical help, while the women tended to provide more personal care.

The discussion group and interview data showed that this group of carers was considerably more likely to feel bitterly resigned to their caring circumstances, particularly when this involved a permanent caring role (as in the case of a child with a debilitating long-term condition). They were

also more likely to have abandoned their own once-held aspirations, especially those relating to having a life of their own and/or hopes for a career. They also reported limited paid employment opportunities, and were worried about reduced pension contributions and feared for their own welfare in old age.

Experience of existing services had led many long-term carers to have good knowledge of what was available to carers from local authorities, but this group also tended to be angry about how difficult it had been to access what few services they had managed to get in place. This contributed to long-term carers' feelings of being unacknowledged in terms of the important role they believe they play in society.

For newer carers in this study, there was, by contrast, a feeling that the care they provide is a duty arising from their relationship with the cared for person. Some felt awkward about receiving money for providing care. Others had experienced many difficulties in adjusting to their caring responsibilities and these had left them clear that they had no choice but to apply for CA and/or other forms of state support.

Carers in the study who were very new to caring expressed aspirations and expectations about having a life of their own/developing a career at a later stage in their lives. However, long-term carers suggested that, in the face of demanding caring responsibilities which could last for years, any such plans were unrealistic.

Sudden onset conditions or sudden transitions which had led to care (such as the birth of a sick or disabled child) had resulted in major adjustments to new carers' lives, as well as to their financial circumstances. These carers had soon found themselves with little social/recreational time and limited opportunities for paid employment. Newer carers were less likely than long-term carers to know how to access and negotiate the system of available services and, since they were also less likely to accept help in a role they believed they had an obligation to fulfil, they were less likely to seek any formal assistance (until it had become impossible to do otherwise).

7.2.6 Other carers

The study also identified a number of other issues relating to other specific groups of carers.

Carers of more than one person were more likely to be female, from a BAME group, and to be caring for a child. One problem commonly discussed by this group was the fact that, even when caring for several people, CA can be claimed only once. This was a significant source of dissatisfaction with CA for those carers in this study who had the most extensive caring roles.

Carers who were living in the same household as the person they cared for were, perhaps predictably, more likely than non co-resident carers to be caring for a spouse or a child, and less likely to be caring for a parent. It was unsurprising that these carers were also more likely to be caring on a long-term basis (five+ years) and for 100 or more hours a week. Co-resident carers were the most likely to have left paid employment in order to care on a full-time basis and more likely to be claiming three or more state benefits.

Those carers who had no qualifications or with only lower level qualifications (below A level) were less likely than those with higher qualifications to have a full-time job, more likely to be caring full-time, and more likely to access two or more state benefits. They were also less likely to prefer to be in paid work.

Those carers with a higher level of qualification were more likely to be a student, to be retired, and to be caring for a child. They were also more likely to say that they had found it difficult to find a job which put their qualifications to good use, and to feel that (for those in work) they had had no choice but to take a job considerably below their skill level.

In all cases of carers who wished to return to education and/or develop new skills which would later give them an advantage in the job market, the 21 hours of study rule (combined with their caring responsibilities) made it difficult to access suitable courses.

Finally, **those carers who were in receipt of two or more benefits** were more likely to be caring for a child, to belong to a BAME group, to be renting their home, and slightly less likely to report financial difficulties than carers with fewer benefits.

7.3 Carer's Allowance and paid employment

A central concern of this study was the role of paid employment in the lives of CA claimants. The great majority of respondents (in both the survey and the forums/interviews) were of working age; this group was more likely than older carers to report financial difficulties and/or to be caring full-time. The issue of paid employment was of great concern to working age carers, as evidenced above.

Comparative data presented in Chapter 6 showed that, when compared with carers in the 2001 Census (most of whom would not have been receiving CA), very few CA claimants have a paid job. This is not surprising given the eligibility rules for CA and the intensive nature of the care they provide, but is also almost certainly a consequence of these factors. Long weekly hours of care (35+) combined with the CA earnings limit (£100 per week) makes finding suitable work extremely difficult for carers in receipt of this benefit (as also evidenced elsewhere and outlined above in Chapter 2).

Jobs with a fixed number of hours and which are flexible enough to accommodate carers' often complex caring responsibilities were, respondents claimed, very difficult to come by. The few suitable jobs available were reported to be low paid (as also found in other research) and require fewer skills than carers feel they can bring to the labour market.

Half the respondents in the survey had given up work at the onset of their caring role. Nearly two-thirds of these had done so in order to provide full-time care (especially men, older carers, and/or carers of older people), while nearly a quarter had done so because they had been unable to negotiate suitable hours with their employer which would enable them to fulfil their caring responsibilities (this was especially true of women and/or carers of a child). Difficulties in adjusting existing employment to accommodate care had often occurred despite employers being sympathetic to carers' responsibilities. In many cases, carers in this study had been conscientious about their inability to fulfil the requirements of their posts while also providing often intensive care. Others carers had developed ill health as a result of trying to combine work and care, and had eventually been forced to give up their paid job.

Some CA claimants in this study had successfully managed to alter their working hours, usually to enable them to remain within the eligibility criteria for CA. Others had moved from full-time to part-time employment rather than try to negotiate more suitable hours, largely because of the difficulties they believed would be involved. Part-time work was particularly valued by the CA claimants in this study as it allowed them to maintain and develop job-related skills, kept them in touch with the job market and fill a gap in their CVs which would otherwise be difficult to explain to future employers, and helped them avoid long-term dependence on state benefits.

A significant number of CA claimants in this study expressed a desire to work once their caring role had ended, and nearly a third would have preferred to be in paid employment at the time of the study. However, only a small number (14 per cent) were actively looking for a job, and carers in the forums and interviews suggested that this was because the eligibility rules for CA were very restrictive and made finding suitable work extremely difficult.

There were some carers in the study who were in paid work. These explained that they had struggled to overcome the difficulties described by others because of the advantages they felt having a job gave them. As well as points already mentioned, these advantages were seen as benefits for their health, self-esteem, and confidence. Paid employment also provided carers with a break, a social life (friendship with fellow employees), and financial compensation. Working carers in this study were more likely than those not in a paid job to think that grappling with the eligibility rules for CA and their associated complications was worth doing in order to benefit from the advantages of having a job.

Not all carers in this study wanted to work. Some regarded the care they provided as in itself a 'full-time job', and emphasised the point that carers are not '*unemployed*'. These carers felt accessing paid employment in addition to their caring role would result in some neglect of or reduction in the quality of care given to the person they cared for, and were unwilling to make this compromise.

7.4 Recommendations

Having summarised above key findings of this new study, the report now turns to their policy implications, and presents recommendations for future policy in this field.

7.4.1 Support and services available to Carer's Allowance customers

- 1 Many CA customers in the study called for changes to the overall system of support for carers, and for this system to be both easier to understand and to access. While this repeats policy recommendations made by previous researchers (see Chapter 2), it is clear that this issue has not been satisfactorily resolved to date. Key aims for the carers studied were to feel better supported in their caring role, to have a 'life of their own', and (for many) to be able to seek and secure paid employment.
- 2 To achieve improvements in carer support, the different parts of the wider system of services and support need 'joined up' practices and arrangements. This is of growing importance given the trend towards 'personalisation' in the provision of services and greater control for sick and disabled people and their carers. CA was frequently described by carers in this study as just one of the many elements of the support they require to cope with their responsibilities; some had experienced much frustration in dealing with many different, and seemingly disconnected, parts of this system. Many also felt that the support available needed to be delivered with a more 'human' approach, and a sounder appreciation of many carers' very demanding caring roles.
- 3 The *Carers (Equal Opportunities) Act 2004* placed a statutory duty on local authorities to inform carers of their rights, and to consider carers' wishes in relation to employment, training and education, yet five years later, awareness of this among carers in the study was limited. Given the evidence in Chapter 5 about the incidence of poor health among the survey respondents (affecting only a minority of carers, but a much larger percentage than found in comparable populations), ensuring CA customers' awareness of their rights is of particular relevance and importance.
- 4 More information about CA should be available, from the first moment carers access support services. There are significant roles here for local medical practices, hospital discharge services, Adults' and Children's services, voluntary organisations, Jobcentre Plus, and the ways all of these use the internet. Carers felt that CA should be far more 'visible' than it is at present, and that the information which is available should be accurate and up to date.

- 5 Staff across the system of care and support who come into contact with carers should have a greater appreciation of carers' very constrained choices. In particular, most carers claim CA out of necessity and sometimes desperation, often after trying to get by without accessing publicly funded support.
- 6 Preventative action in the system of care and support is greatly needed, but frequently lacking; some CA customers in this study said they had received 'no help' (by which they often meant help from social services) until they encountered a 'crisis' in their caring situation. This had had a negative impact on their health and well-being and some felt it had limited their access to paid employment, with serious consequences for their financial situation. A key recommendation is for more investment in preventative approaches which would support carers at earlier stages in their caring roles.
- 7 Feeling that they are socially recognised and appreciated was a very important issue for carers in this study. A sense of being appreciated for the role they play in society, they felt, would help them to feel less isolated and unhappy. To improve the well being of CA customers it is recommended that this perception is also kept firmly in view; and that any new arrangements should achieve a co-ordinated combination of practical support, adequate financial assistance, and respect and acknowledgement of carers' contribution.
- 8 Some of the younger carers in the study, and those new to caring, felt a degree of both guilt and embarrassment when seeking financial support for the care they provide. For this group, clarifying the meaning and purpose of CA would be beneficial. It is recommended that in making any changes to CA, its importance as an acknowledgement of caring roles as well as an income maintenance benefit should still be retained: this might involve separating different elements of the financial support carers can claim.
- 9 The eligibility rules for CA were regarded as particularly problematic by carers when they tried to seek paid employment or to access training or education. They found that these rules limited them to low paid unskilled work, and to a narrow range of courses. The widely accepted importance of enabling carers to combine work and care implies that these rules, also the subject of widespread previous critical comment, should also be reviewed.
- 10 Many carers called for more discretion on the part of the CAU staff when their applications were assessed, or when they were liaising with the CAU about existing claims. This, they felt, was especially important when they were trying to combine their care with paid employment which generated variable earnings which were not the same each week. This would help reduce some of the tension and uncertainty involved in their caring lives.⁴¹
- 11 Although many carers in the study felt that CA was easier to apply for than other benefits, some believed the application process for CA could be less intrusive and that it should demonstrate a greater degree of trust on the part of assessors. While this was not identified as a major issue in other recent research (NAO 2009), vigilance on this point in the delivery of this support to carers remains important.
- 12 Carers in this study had experienced many difficulties and much confusion in the way the CA they received interacted with other benefits which they, or those they cared for, were claiming. This should be addressed, particularly in the way it relates to IS, but also to address carers' perception that CA is 'taken away' when they reach retirement age and start to receive State Pension. The concept of 'overlapping' benefit entitlements is extremely hard for carers to understand and accept. This point should be considered in any reform of CA and the wider benefits system.

⁴¹ CAU staff who participated in the study reported that they always try and achieve the best outcome for the customer.

7.4.2 Responding to different Carer's Allowance customers' needs

This study showed that different CA customers have different needs. It is recommended that these are borne in mind in making any changes to the financial and other support available to carers.

- 13 Younger carers (under age 35) would benefit most from greater sensitivity to their long-term needs. Many are caring for a sick or disabled child and miss out on career opportunities; some feel trapped, long-term, on benefits. More effective implementation of existing support for carers would help many of these carers to secure part-time employment while also providing care, keeping them in touch with the job market and benefiting from the advantages of having a job.
- 14 For older carers, it is important to address the issue of how CA interacts with State Pension, and the approach recommended in the House of Commons Work and Pensions Committee (HoC WPC) report may offer a suitable way forward here (this would involve allowing this group of carers to retain a Caring Costs payment, although the income maintenance element of their CA would be lost)⁴².
- 15 Carers of a spouse are often men and many in this study received little support in their caring role apart from CA. We recommend that the needs of this group be more explicitly considered in the development of support for carers in the future.
- 16 The CA customers in this study were much more likely than other carers to be in poor health. It is recommended that the health of CA customers (compared with other carer groups and the general population) should be a focus of further research to establish how robust this finding is. Poor carer health inevitably leads to additional costs in the health and social care system, and CA customers may need to be particularly targeted in efforts to promote carer health and well-being.

7.4.3 Carer's Allowance customers' ability to combine work and care

The study showed that CA customers were still finding it very hard to access paid employment alongside their caring roles, although many wished to do so. Paid employment was crucial for most CA customers in the study, as having a job was the best way they could cope with their demanding caring roles. It allowed them to take a break from caring; offered them self-esteem, confidence, greater health, and a social life; kept them in touch with the labour market, with a view to returning to work at a later date, when their caring duties were less onerous or had ceased entirely; and had the potential to make a major difference to their financial circumstances.

- 17 Despite this perception, most carers in the study had been forced to give up their paid jobs because of their caring responsibilities. This arose from the complexity of caring and the difficulty in negotiating suitable working hours. Because combining work and care is so fundamentally important for carer well being, it is recommended that further effort be put into providing a wider range of support services designed to support working carers, and to raise employers' awareness of how their approach to designing jobs and supporting their employees who acquire caring roles can help. Amending the earnings limit rules for CA is also a key element in improving this aspect of support for carers.

⁴² Pension Credit is awarded to pensioners on low incomes. If CA is awarded to a Pension Credit recipient, they will receive a Carer Premium.

Appendix A

Methodology

Literature review

A literature review of government, academic and independent sector research was conducted examining material published from 2006 onwards.

Carers Advisers: telephone interviews and discussion forum

To seek baseline information about Carer's Allowance (CA) and its role in carers' lives, the study's first stage of data collection involved a number of interviews with carer advisers. These took two forms:

- 1) One-to-one telephone interviews with carer advisers representing a number of national and regional organisations. Appropriate agencies and organisations were contacted by letter or email and invited to participate.⁴³ The interview schedule (Appendix B.1) was designed on the basis of information identified in the literature review. Carers advisers represented a range of organisations, including the Carer's Allowance Unit (CAU), Carers UK, Carers Direct, Princess Royal Trust for Carers and Crossroads Care, a City Council in the north of England, a District Council in Scotland, two carers' organisations in two London Boroughs, and a policy advisor at DWP.
- 2) A focus group involving staff (ten) from the CAU, including those who process CA claims and make decisions on applications (the topic schedule can be found in Appendix B.2). The discussion was tape-recorded and transcribed in full to facilitate data analysis. Following the focus group, an additional telephone interview was arranged with a CAU appeals officer (the topic schedule can be found in Appendix B.3).

Questionnaire survey of CA recipients

A four-page survey was designed to capture key information from CA recipients (see Appendix B.4). The survey was piloted with 21 carers who participated in the two pilot discussion forums (see below). 1,600 copies of the survey were then distributed to CA recipients whose contact details were supplied to the research team by DWP.

The purpose of the questionnaire was two-fold to:

- 1) acquire key statistical data on a large number of CA customers; and
- 2) use as a basis for recruiting participants to the carers forums and interviews. All who replied were entered into a prize draw for £100. 504 surveys were returned.

Discussion forums with carers

Eight carer forums, each involving between eight and 11 CA claimants, were conducted in four different locations in the UK: two in London, four in two areas in the north of England, and two in Scotland. These venues were selected in order to draw on a range of different carer perspectives. The first two forums (which served as pilots) were organised via a carers' organisation based in one

⁴³ Only a few organisations were unable to provide a suitable candidate, and this was usually as a consequence of existing work commitments.

of the north of England areas and its participants recruited via the organisation’s regular newsletter. The participants in the remaining six forums were recruited from consenting respondents to the survey.

The topic schedule (Appendix B.5) was based on information identified in both the literature review and the interviews with carers’ advisers. Each forum was tape-recorded to provide verbatim quotations. All the forums lasted around two and a half hours. All participants who took part in the forums were offered a gift (value £30) to thank them for their contribution. The respondents in each forum were selected according to shared characteristics identified in the literature review as relevant to CA. The eight forums’ ‘themes’ are listed in Table A.1.

Telephone interviews with CA recipients

The final stage of data collection involved in-depth telephone interviews with ten CA recipients who had volunteered via the survey. The purpose of this stage of research was to explore in detail some of the issues which arose in the carers’ forums, including any which might have been difficult to disclose in a social gathering (e.g. financial or personal matters). The interviews were also an opportunity for carers to tell a ‘story’ about how they came to be a carer and to claim CA.

The interview schedule (Appendix B.6) was based on information identified in the literature review, the carer advisers interviews, and the carers’ forums. Each interview lasted between 30 and 45 minutes and was tape-recorded to facilitate analysis. A gift (value £20) was given to respondents to thank them for their contribution.

Table A.1 CA customers’ discussion forums by ‘theme’

| Forum ‘theme’ | Venue | Number of carers at the forum | Forum code |
|--|----------------------|-------------------------------|-------------------------|
| Carers of a person aged 21-65 with a long-term condition or disability | London | 9 | Forum: LLTC |
| Carers who started their CA claim within the last 24 months | London | 7 | Forum: new to CA |
| Carers of an older person | North of England | 10 | Forum: Older Person |
| Carers of a sick or disabled child | North of England | 11 | Forum: Child |
| Carers who wish to or are seeking to return to paid work | North of England (2) | 11 | Forum: Seeking Work |
| Carers in paid work (earning <£95 per week) | North of England (2) | 8 | Forum: Working |
| Carers with complex benefit profiles (at least 4 benefits) | Scotland | 8 | Forum: complex benefits |
| Carers who have been caring for 8+ years | Scotland | 9 | Forum: LT care |

Appendix B

Research instruments

B.1: Carer advisor topic guide

1. About you and your job role

Could you start by briefly outlining your role within [...name of organisation]?

(Establish how long in role and extent of contact with CA claimants.)

2. Contact with Carer's Allowance claimants

2a. *Can I start by asking you about the way CA claimants approach you/your organisation:*

Probes:

- How do carers first get in touch with you? (May be various routes)
- Are they ever referred by another agency? (If so, which?)

2b. *I am also interested in the kinds of support your organisation gives to CA claimants. Could you start by summarising what you provide?*

Probes:

- Does your organisation offer any general guidance to carers about claiming CA? (Leaflets, website, etc.)
- What about personal contact and any specific queries individuals may have? (What does this consist of? By phone? Drop-in centres? Are there specialist staff dedicated to this – how many and what training is given to advisers?)

2c. *Could you next say something about the kinds of queries and concerns carers raise with you about CA, and how you respond to these?*

Probes:

- What (if anything) do most carers know about the rules for claiming CA when they contact you?
- How well do you think the rules are generally understood?
- What aspects of CA do carers need particular help with?
- Do you have to deal with any common problems?
- How do you resolve these?
- Do any issues arise with carers because they (or the person they care for) are claiming other benefits?
- Do you ever get queries from carers whose circumstances have changed?

- Do you (or anyone else in your organisation) ever have direct dealings with the DWP CA Unit?
- Can you give us any idea of how many enquiries from carers your organisation deals with (e.g. daily/weekly)? How variable is this?

2d. *I would also like to talk to you about your own knowledge of CA claimants arising from your experience of advising them:*

Probes: Age, gender, ethnicity, caring situation, family/household situation, employment situation of the carers they come into contact with.

Probes: again for the carers they come into contact with:

Carers wanting to make a claim, seeking information about what they are entitled to

Carers needing advice about a change in their caring circumstances

Carers needing advice about a change in their employment circumstances

Carers wanting advice about specific rules or decisions about their claim

Carers wanting advice or support in appealing against a decision about CA

- What motivates the carers you deal with to apply for CA at a particular point in their caring situation?
- Do carers ever comment on what they think CA is for? What do they say?
- Do carers ever tell you what they spend CA on?
- Are there any common ‘myths’ and misunderstandings about CA?
- Do you ever come across carers who have been given incorrect information? Where has this come from?

3. CA claimants and employment

3a. *We are particularly interested in how claiming CA interacts with carers’ employment experiences or attitudes to combining paid work with their unpaid caring roles:*

Probes:

- Do you get enquiries from CA claimants wanting support in combining work and care?
- What advice or support do you give them?
- Can you give any examples of how claiming CA has affected a carer’s job or employment circumstances?

(We don’t need any names or personal details, but are interested in real examples you have dealt with)

3b. *We're also interested in whether CA recipients are getting information about CA (or other benefits) and paid work from other sources.*

Considering the claimants' you speak to:

Probes:

- What sources of information do the claimants mention as having informed them about benefit options?

Probe: are they getting information and advice from employers/prospective employers; employment agencies; from local authorities (e.g. social workers) etc.

- How satisfied/dissatisfied would you say CA recipients are with:
 - The information they can get for themselves about CA
 - The way their CA claims are processed by officials
 - The forms they have to fill in
 - The way CA interacts with/is linked to other benefits they or the person they care for is receiving
 - The limit on earnings for CA recipients
 - The level of CA

4. Future changes to the benefits system

4a. *Based on your own experience of dealing with CA claimants, are there any changes you personally would like to see in the official arrangements for CA?*

Probes:

- What is the most important thing you would like done to improve the way CA works for carers?
- And specifically thinking about carers who wish to work, how could CA be altered to better address their needs?

4b *Finally, does your organisation have any of the following:*

- An official statement of its views on CA.
- Any data on the number of queries received from CA claimants and the nature of their queries and/or the carers' circumstances.
- Any other documentation which you think would be useful to our study.

If yes to any of the above, request copies and check whether these documents can be referred to in the report of the study.

B.2: Topic guide for Carer's Allowance Unit forum

1. **Carers' applications through the Carer's Allowance Unit...**

- How have the carers arrived at CAU – signposting by other agencies? If so, which and what difference (if any) does this make?
- Do advisors work with written 'scripts' while processing claims?
- Are most carers aware of the Carer's Allowance rules when they apply?
- What aspects of CA do carers need particular help with from the CAU?
- In what circumstances would CAU advisors engage with 3rd parties acting on a carer's behalf?
- Does the CAU ever signpost claimants to other agencies?
- How many claims does an advisor deal with daily/how variable is this?
- How does the appeals procedure work?

2. **Difficulties for carers while claiming Carer's Allowance...**

- What problems/misunderstandings are common? How are these resolved?
- How are any payment issues relating to banking handled?
- Do all CAU staff deal with 'difficult' cases? Are there any specialist advisors?
- Where CA interacts with other state benefits, what kind of problems does CAU have to deal with?

3. **Changes in claimants' circumstances...**

How is the CAU involved when:

- A claimant's caring ends (e.g. if the cared for person dies or goes into residential care/hospital)?
- If there is a transition in care (e.g. when a disabled child becomes an adult)?
- When a carer takes on care for more than one person?

4. **CAU advisors' perceptions of claimants...**

- How would CAU advisors describe the carers who typically apply for Carer's Allowance? Are there distinctive groups with similar characteristics?
- What factors motivate carers to apply for CA via the CAU?
- What do carers think Carer's Allowance is for (wage, acknowledgement, etc)?
- Does the CAU have any understanding of what carers spend Carer's Allowance on?

5. Carer's Allowance claimants and employment...

- Do most carers contacting CAU find the work/care rules easy to understand?
- How common is it for Carer's Allowance claimants to express a desire to return to work, and what advice is given?
- How are issues relating to employment dealt with (e.g. if a carer has a pay rise or changes their working hours)?
- What support is offered to Carer's Allowance claimants seeking work?

6. Sources of information carers typically draw upon to become informed about Carer's Allowance...

- How much information does the CAU provide?
- Are carers satisfied with the information that is available via the CAU?

7. Changes to existing services...

- What other information would CAU advisors offer?
- Other forms of support?

B.3: Appeals officer (Carer's Allowance Unit) topic guide

1. **Could you start by describing the Carer's Allowance appeals procedure?**
 - How are carers referred to the Appeals team?
 - Are there any formal procedures to follow?
 - What is involved (additional paperwork/communication, etc)
 - How long does an appeal typically take?
 - Do you have data relating to numbers of appeals? Personally?
 - Have you conducted internal research on appeals?
2. **What issues are typically involved in the cases of carers who make appeals?**
 - Misunderstandings (carer/other)?
 - Complicated carer circumstances?
 - Employment issues?
 - Other?
3. **How are Appeal decisions typically made?**
 - What issues are taken into account?
 - Do you have a level of discretion?
4. **Are there any particular groups of carers who tend to make appeals?**
 - Carers of certain people/condition?
 - Carers with specific characteristics?
 - Carers with certain benefits 'packages'?
 - Other?
5. **Are carers who make appeals ever represented by a third party?**
 - Eg, solicitor, Carers' Organisation, etc.
6. **Based on your own experience of dealing with CA claimants, are there any changes you would personally like to see in the official arrangements for CA?**
7. **Are there any other issues that you feel are relevant to the CAU appeals procedure?**

B.4: Carer's Allowance survey



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Developing a clearer understanding of the Carer's Allowance customer group

To find out more about the situation of carers who receive Carer's Allowance, we are inviting you to complete this questionnaire as part of a study funded by the Department of Work and Pensions.. Please spare a few minutes to answer some questions about your caring situation. Any personal information you provide will be treated in confidence. **Any information you provide will not affect any benefits you are claiming now or in the future.** Further information about the study is given in the accompanying information sheet.

Your caring situation

1. For how many people do you provide regular care? _____ person(s)

(By regular we mean on a weekly basis or more frequently. **If more than one person, please answer the questions below in relation to the person you provide the most care for**)

2. The person I care for is ...

please tick **one** box only

My spouse/partner ☐
 My grandparent ☐
 My adult child (aged 20 or over) ☐
 Other relative/family member ☐

My parent/parent-in-law ☐
 My child/grandchild (under 20) ☐
 Friend/neighbour ☐
 Other ☐

If other, please specify _____

3. How old is the person you care for? _____ years

4. How long have you cared for this person? _____ years _____ months

5. Does the person you care for live in the same household as you?

Yes ☐

No ☐

Sometimes ☐

6. In an average week, how many hours do you spend providing care for this person?

Please indicate to the nearest hour _____ hour(s)

7. What kind of care do you provide for this person?

please tick **all** that apply

| | |
|--|--------------------------|
| Personal care (e. g. dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet) | <input type="checkbox"/> |
| Physical help (e. g. with walking, getting up and down stairs, getting into and out of bed) | <input type="checkbox"/> |
| Practical help (e. g. preparing meals, shopping, laundry, housework, household repairs, taking to doctor/hospital) | <input type="checkbox"/> |
| Giving medicines (e. g. making sure he/she takes pills, giving injections, changing dressings) | <input type="checkbox"/> |
| Helping with paperwork / financial matters (e.g. letter writing, form completion, money management, record-keeping for direct payments) | <input type="checkbox"/> |
| Visiting / keeping him/her company / providing emotional support, motivation or supervision (e. g. visiting, sitting with, reading to, talking to, playing cards or games) | <input type="checkbox"/> |
| Taking him/her out / supporting leisure activities (e. g. taking out for a walk/drive, or to see friends or relatives) | <input type="checkbox"/> |
| Managing or planning their other care support arrangements (e.g. seeking information about community services; arranging services) | <input type="checkbox"/> |
| Keeping an eye on him/her to see he/she is all right? | <input type="checkbox"/> |
| Other (please specify) | <input type="checkbox"/> |

You and Carer's Allowance

8. How long have you been receiving Carer's Allowance? _____ years _____ months

9. Apart from Carer's Allowance do you personally receive any of the following benefits?

*please tick **all** that apply*

- | | |
|--|--|
| Job Seekers Allowance <input type="checkbox"/> | Council Tax Benefit <input type="checkbox"/> |
| Housing Benefit <input type="checkbox"/> | Disability or Severe Disability Premium <input type="checkbox"/> |
| Income Support <input type="checkbox"/> | Severe Disablement Allowance <input type="checkbox"/> |
| Statutory Sick Pay <input type="checkbox"/> | Blue Badge <input type="checkbox"/> |
| Invalidity Benefit <input type="checkbox"/> | Motability Help <input type="checkbox"/> |
| Disability Living Allowance <input type="checkbox"/> | Independent Living Fund <input type="checkbox"/> |
| Attendance Allowance <input type="checkbox"/> | Access to Work <input type="checkbox"/> |
| Social Services Direct Payments <input type="checkbox"/> | Working Tax Credit <input type="checkbox"/> |
| Disability or Severe Disability element of Working Tax Credit <input type="checkbox"/> | Child Tax Credits <input type="checkbox"/> |

Any other benefit not mentioned (please specify) _____

10. Which of the following statements best describes the main way you spend Carer's Allowance?

*please tick **one** box only*

- | | |
|---|--------------------------|
| I use it for my regular caring expenses | <input type="checkbox"/> |
| I set it aside for emergencies relating to the care I provide | <input type="checkbox"/> |
| I use it for travel costs (this can include running a car) | <input type="checkbox"/> |
| I save it for holidays and/or breaks from caring | <input type="checkbox"/> |
| I treat it as part of my weekly income and spend it on general household expenses | <input type="checkbox"/> |
| I use it mainly for my own recreational/social activities | <input type="checkbox"/> |
| I save it up to cover the costs of caring if I am ever ill | <input type="checkbox"/> |

If you spend your Carer's Allowance in other ways, please state _____

You and your other circumstances

11. Which of the following best describes your circumstances over the last seven days?

*please tick **one** box only*

- | | |
|---|--|
| In paid work full-time (30 hrs+ per week) <input type="checkbox"/> | In paid work part-time (fewer than 30 hrs a week) <input type="checkbox"/> |
| Looking for work/unemployed <input type="checkbox"/> | Retired from paid work <input type="checkbox"/> |
| Permanently sick/disabled <input type="checkbox"/> | Student <input type="checkbox"/> |
| Looking after family (or caring) full-time <input type="checkbox"/> | Other <input type="checkbox"/> |

If other, please specify _____

12. If you are currently in paid work, please tell us what kind of employer you work for:

- | | |
|------------------|--------------------------|
| Public sector | <input type="checkbox"/> |
| Voluntary sector | <input type="checkbox"/> |
| Private sector | <input type="checkbox"/> |
| Self-employed | <input type="checkbox"/> |

Please state your job title _____

13. If you are currently in paid work, have you ever altered your working hours or has your employer made special provisions for you . . .

- | | | |
|---|------------------------------|-----------------------------|
| Because of your caring responsibilities | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Because of the rules for claiming Carer's Allowance | Yes <input type="checkbox"/> | No <input type="checkbox"/> |



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14. If you are **not** currently in paid work, have you given up work to care? Yes ☐ No ☐

If yes, please state why . . .

Unable to negotiate suitable working hours ☐

More time needed to manage caring role ☐

Difficulties or disputes with employer ☐

With Carer's Allowance, I no longer needed additional earnings ☐

Carer's Allowance rules mean it's not worth my while to go on working ☐

Other (please state) _____

15. If you are **not** currently in paid work, which of the following statements best describes your situation?

I would prefer to be in paid work ☐

I am looking for paid work ☐

I prefer not to have a paid job ☐

I would like to work once caring role ends ☐

16. Which of the following describes your qualifications? please tick **one** box only

No qualifications ☐

A vocational qualification (please state) _____ ☐

Qualifications up to GCSE level ☐

A-Levels or equivalent ☐

Undergraduate degree ☐

Postgraduate degree ☐

17. How well would you say you are managing financially these days? Would you say you are . . .

please tick **one** box only

Living comfortably ☐

Doing all right ☐

Just about getting by ☐

Finding it quite difficult ☐

Finding it very difficult ☐

Don't know ☐

Some questions about you

18. Are you: Male ☐ Female ☐

19. How old are you: 16 – 24 ☐ 25 – 34 ☐
35 – 49 ☐ 50 – 59 ☐
60 – 64 ☐ 65 or older ☐

20. What is your ethnic group? please tick **one** box only

| White: | Mixed: | Asian or Asian British: | Black or Black British: | Chinese or other ethnic group: |
|----------------------------------|--|--------------------------------------|--|---|
| White <input type="checkbox"/> | White and Black <input type="checkbox"/> | Indian <input type="checkbox"/> | Black <input type="checkbox"/> | Chinese <input type="checkbox"/> |
| British <input type="checkbox"/> | Caribbean <input type="checkbox"/> | | Caribbean <input type="checkbox"/> | |
| White <input type="checkbox"/> | White and Black <input type="checkbox"/> | Pakistani <input type="checkbox"/> | Black African <input type="checkbox"/> | All other ethnic <input type="checkbox"/> |
| Irish <input type="checkbox"/> | African <input type="checkbox"/> | | | groups |
| White <input type="checkbox"/> | White and Asian <input type="checkbox"/> | Bangladeshi <input type="checkbox"/> | Other Black <input type="checkbox"/> | |
| Other <input type="checkbox"/> | | | groups | |
| | Any other Mixed <input type="checkbox"/> | Any other <input type="checkbox"/> | Any other <input type="checkbox"/> | |
| | background | Asian <input type="checkbox"/> | Black <input type="checkbox"/> | |
| | | background | background | |

Please turn over

21. Over the last twelve months would you say your health has on the whole been:

*please tick **one** box only*

- Good
- Fairly good
- Not good

| |
|--|
| |
| |
| |

22. Which of the following best describes the housing you occupy?

*please tick **one** box only*

- I/we own my/our home (with or without a mortgage)
- I/we pay rent for my/our home (from a private or social landlord or local authority)
- Other (please specify below)
- Other: _____

| |
|--|
| |
| |
| |

23. How many people live in your household (including yourself)?

Number

| |
|--|
| |
|--|

Of the people in your household, how many are:

- Children aged 0-19 years who have a limiting long term illness or disability?
- Children under 5 or in full-time education (who do NOT have a limiting long term illness or disability)
- Cared for adults with a limiting long term illness or disability
- Other people not requiring unpaid care, including yourself if applicable

| |
|--|
| |
| |
| |
| |

Follow up discussion forums and interviews

As described in the covering letter which accompanied this questionnaire, we are currently looking for carers in receipt of Carer's Allowance who are willing to help us further with this study. This would involve taking part in a discussion forum (along with other carers) or agreeing to a one-to-one telephone interview with a member of the research team. A cash gift will be offered to all carers who are selected to participate in either part of the study (this gift will not affect your Carer's Allowance or other state benefits).

If you do **NOT** wish to be included in this part of the study, please tick here: ☐

If you do **NOT** wish to be included in the prize draw, please tick here: ☐

CONTACT DETAILS (so that we may contact you again and include you in the prize draw)

Name _____

Address _____

Postcode _____

Phone number _____ **Email address (optional)** _____

Thank you for your time.

If you have any questions about the study or about this questionnaire, you can contact the research team by calling us on _____, or by sending an email to CIRCLEadmin@leeds.ac.uk

Professor Sue Yeandle, CIRCLE, University of Leeds, LS2 9JT

If you have any questions about the commissioning of this research by the Department for Work and Pensions, please contact:

B.5: Carers' forum topic guide/discussion themes

Experience of caring

- Intensity/duration/nature of their caring experience.
- How claimants 'manage' to care.
- Their coping strategies and the adjustments they have made in their everyday lives.
- What (if any) sources of support they access (services, networks, family etc).
- Their attitudes to available carer support/services (quality, flexibility, responsiveness, etc.)
- Their experience (if any) of Carers Assessment.
- Their key concerns about their caring situation.
- Their personal aspirations.

Benefits history and financial issues

- Claiming CA – background to their claims: How did they find out about CA? why, when – How long had they been caring before they made a claim for CA? perception of choice, application procedure, advice received, changes, etc. What prompted them to make a claim for CA? (i.e. if the customer had been caring for a while, what was the tipping point for making a claim for CA?)
- Awareness of other benefits and clarity about the benefits they receive.
- Specific costs they incur in their caring situation.
- How CA fits into their financial management and planning:
 - Set aside for emergencies?
 - Spent in routine household budgeting?
 - Used for other specific purposes?
- Importance of CA to claimants, and why – financial/social/identity aspects.
- Claimants' wider attitudes to seeking/receiving state financial support.

Paid employment

- Main ways in which caring has changed their experience of work.
- The journey they have undertaken in taking on their caring role and how this has affected their career or job and their employment aspirations.
- Scope for other activities, work, a life of their own.
- Content or wanting change – what would their preferred work/care arrangement be?
- How/why/when do claimants change job status/working hours.
- Main challenges of combining care with employment.
- What helps carers to combine work and care effectively.
- Practical issues in combining work and care when claiming CA:
 - Paperwork, negotiations about CA with employer.
- Is combining work and care worthwhile, (in view of current CA rules).
- How well does CA work – and what would make it work better for them?

B.6: Carer Interview Topic Guide

1. About you and your caring responsibilities

1a. *Could you start by telling us about your caring role and the person you care for... ?*

- Who do you care for, and what is his/her condition?
- For how long have you cared for him/her?
- What, weekly, is the intensity of the care you provide?
- What kind of care do you provide? (Describe a 'typical day')
- Do any specific costs arise as a result of the care you provide?

1b. *We would like you to tell us about how you manage your daily caring responsibilities...*

- Does anybody else help you in your caring role (i.e. family, friends, caring support agencies), and if so, could you tell us about this?
- What adjustments to your life have you had to make as a result of your caring role? How do you cope with it?
- Have you ever had a Carer's Assessment?
- What are your main concerns as a carer?
- What personal aspirations do you have?

2. Benefits history and CA

2a. *Could you describe your caring situation when you first applied for CA?*

- How did CA fit in with your caring situation?
- What was your attitude to claiming state benefits? Is this different from now?
- What led you to apply for CA?

2b. *Could you tell us how you first heard about CA?*

- What was the most useful source of information about CA?
- What did you know about CA before you first claimed it? How long had you been caring before this stage?
- Did you have any misunderstandings about CA in the early stages? (Where did these come from?)

2c. *How did you find the process of applying for CA?*

- Did you receive any help when applying for CA? How did you value this help?
- How did you find the process of applying for CA? (Form difficult, etc?)
- How long did your CA application take before you received the benefit? Was this processing time acceptable to you?
- Did you ever access the Appeals process?

- 2d. *Could you tell us what you typically spend CA on?*
- How does CA fit in with your other financial circumstances?
 - How important is CA to you as a source of income?
 - What do you think CA should be spent on? Is this different from what you do spend it on?
- 2e. *What are your feelings about the rules of eligibility for CA?*
- Do you find the rules easy or difficult to understand?
 - Which CA rules affect your caring circumstances, and in what ways?
 - How would these rules need to change to better accommodate your caring role?
- 2f. *Which (if any) state benefits other than CA do you claim?*
- How do these benefits interact with CA?
 - What (if any) complications have emerged from combining benefits (including CA)?
 - How do benefits impact upon your caring role?

3. CA claimants and employment (or education, if interviewee is studying)

- 3a. *We are particularly interested in how claiming CA interacts with carers' experiences of paid employment or attitudes to combining paid work with unpaid caring roles. Could you describe how your caring responsibilities have impacted upon your working life?*
- If you have tried to combine work with care, what have been the difficulties? (negotiations with employer, flexibility in the workplace, etc)
 - If you have given up work to care, why did you do so?
 - What is the value of work to you? (financial, psycho-social, etc)
 - Would you rather be in paid work, and/or how would this differ from your current circumstances?
- 3b. *How has CA impacted upon your relationship with paid employment?*
- How have the eligibility rules for CA relating to paid employment affected your decisions about paid work? (working hours/study rule limit)
 - What is your experience of applying for jobs while receiving CA? (limitations of part time work, etc)
 - What impact (if any) does being in receipt of CA have on your capacity to seek and maintain paid employment?

4. Changes to CA

- 4a. *Finally, we're interested in any suggestions you might have about improving CA for carers.*

5. Do you have any other comments about anything else related to Carer's Allowance or the care you provide?

Appendix C

Research documents

C.1: Letter to carers accompanying survey

Developing a Clearer Understanding of the Carer's Allowance Customer Group: new research

I am writing to ask for your help with a study of Carer's Allowance customers being undertaken during autumn/winter 2009-10, led by Professor Sue Yeandle at the University of Leeds. This piece of research is being funded by the Department for Work and Pensions (DWP).

Your name and address were forwarded to us by the Department of Work and Pensions, which has commissioned the study because it needs better information about Carer's Allowance customers particularly about their experiences of claiming Carer's Allowance, their experience of caring, and their choices and decisions about caring and paid employment.

We would like you to complete and return the enclosed questionnaire (a pre-paid addressed envelope is included for this) as soon as you can, preferably within the next week. The questionnaire has been tested with the help of other carers, and we hope it will take less than 15 minutes of your time.

The study will also include telephone interviews with carers receiving Carers Allowance and a series of discussion forums in England and Scotland (including in the area where you live). Some carers will be invited to take part in these and we hope you would be willing to do this if invited. To ensure we do not intrude on Carers Allowance customers who would not wish to take part in these aspects of the study, you are asked at the end of the questionnaire to let us know if you are sure you would NOT wish to be involved in the forums or interviews.

Participation in this research is voluntary and will have no effect on any benefits claims you may be making, now or in the future. The information you provide by returning the enclosed questionnaire will be confidential to the research team. Any individual comments received during this research will be anonymised and will be stored in a secure place. You have the right to withdraw from the research process at any time.

The study has been designed in accordance with appropriate research ethics. Respondents' rights and privacy are paramount and no personal information about individual participants in the study will be passed to the DWP or shared with any other organisation. All information shared with the research team will be treated as completely confidential, and no participant will be named or identified in the final report.

If you have any questions about the study, please contact _____, DWP Project Manager
on _____ or email _____, a member of the CIRCLE
research team (telephone _____ or email _____). I very much hope
you will agree to help make the study successful in collecting information about carers in a wide
range of circumstances, and thank you in advance for your time.

Yours sincerely

Professor Sue Yeandle

C.2: Letter inviting carers to participate in forums

Developing a Clearer Understanding of the Carer's Allowance Claimant Group: new research

Thank you for agreeing to our recent telephone invitation to participate in a Carers' Forum from [TIME AND DATE] at [LOCATION].

The forum will take approximately two hours (with a break for lunch midway through). 10 to 15 carers who receive Carers Allowance have been invited to come along to discuss topics about caring and claiming this benefit. The discussion will be led by a member of our research team. All carers who accept our invitation and participate in the forum will receive a gift of £30 as a token of our thanks for giving up their time to do this.

We realise that some carers may need to make alternative care arrangements for the person they support in order to attend the forum. If this is the case, please contact Ben Singleton at CIRCLE (see contact details below), who will be able to advise you on reclaiming the cost of the care you need. We have a limited budget for this, but hope it will be adequate to cover your costs; please discuss these in advance to confirm that your costs are eligible.

Although your details were provided to us by the Department for Work and Pensions (DWP), we want to reassure you that participation in this study is completely voluntary and will have no effect on any claims you may be making. No information you give about your personal circumstances will be relayed to the DWP, and your name and personal details will not be used in our study report.

If you have any questions about the DWP's aims in commissioning the study, please contact _____, DWP Project Manager on _____ or email _____

if you have any questions you would like to ask the research team, please contact me _____, research officer at the University of Leeds on _____ or email _____

Yours sincerely,

Ben Singleton

C.3: Information/consent form used in forums

Developing a clearer understanding of the Carer's Allowance claimant group: Carers' Forum

Dr Gary Fry from CIRCLE (the Centre for International Research on Care, Labour and Equalities) at the University of Leeds will be leading the discussion in today's forum. Ben Singleton may not contribute during the discussion, but he will be making notes, to help us produce an accurate record of the session. Please note that he will not be documenting any details which would make any individual attendees identifiable. Both researchers will be happy to talk to you about the research and answer any questions you may have during today's break or after the session. Gary Fry and Ben Singleton are both members of a research team for this project led by Professor Sue Yeandle at CIRCLE. As CIRCLE members, both Gary Fry and Ben Singleton have strong backgrounds in social research. Much of CIRCLE's research focuses on care-related issues and its relevance to public policy. Details about the different aspects of this research project are available in the accompanying project information sheet.

The Department for Work and Pensions (DWP) has commissioned this study with the aim of gaining better information about claimants of Carer's Allowance. It is keen to know more about their history of claiming benefits, their experience of caring, and their decision-making about paid employment. DWP sees the study as an important way of finding out more about its Carer's Allowance customers, and we are very grateful to you for agreeing to help us with the study. Our questions today will focus on your experiences of caring and claiming Carer's Allowance, and what effect this may have had on any employment related decisions you have made.

With your permission, we would like to record the forum discussion. This will allow the conversation to be listened to again if needed. We will ask your permission and inform you when we have begun recording. If any member of the forum does not wish to be recorded we will respect their wishes and proceed without recording.

Your **rights and privacy** are important to us. We stress that **no personal information you give will be passed to the DWP or shared with any other organisation**. Personal information given in the forums is shared only with other members of the research team, all of whom will treat it as **confidential**. **Participation is voluntary and will not affect any benefits you are claiming, now or in the future. You have the right to withdraw from the forum at any time. You will not be named or identified in any report or publication arising from this study.**

Further information

If you require further information about this research, please contact _____, Research Office, who will be able to answer your queries:

_____, Tel: _____, Email: _____

I can confirm that I have seen the information provided about Carers' Forum in [LOCATION] and consent to information I give during the session being used to inform the research.

Name..... Date..... Signed.....

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This study explores the caring situations and other circumstances of carers who receive Carer's Allowance (CA). Almost one million carers who provide 35 or more hours of care to a person in receipt of certain qualifying benefits are entitled to CA, and over half a million were 'in payment' in 2009. This report is based on survey data from over 500 current CA recipients, and qualitative data from 83 of these, a review of previous literature and new analysis of official Department for Work and Pensions' statistics on the full range of CA customers.

The study highlights CA customers' wide range of demanding caring roles, (in most cases supporting a son, daughter, parent or spouse with a serious illness or disability). It draws attention to their relatively poor health, to the challenges they face in managing their caring situation, often with limited support, and to their difficulty in combining their caring with paid work. The study, and the recommendations it makes, draws particular attention to the services and support needs of CA customers, their aspirations relating to paid employment, and how the design of CA – including the rules on eligibility for CA and the limit on CA customers' earnings from paid work – interact with carers' other benefits and with other services and support carers may receive. The report concludes that a review of CA features relating to these issues is particularly important for the well-being and longer-term financial security of this group, and for their sense of being valued for their role by society at large.

If you would like to know more about DWP research, please contact:
Kate Callow, Commercial Support and Knowledge Management Team,
Upper Ground Floor, Steel City House, West Street, Sheffield, S1 2GQ.
<http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>

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